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Investigation and Identification of Patients with Enhanced Care Needs after Knee Replacement Surgery

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DOI (link to publication from Publisher):
[10.54337/aau466404114](https://doi.org/10.54337/aau466404114)

Publication date:
2021

Document Version
Publisher's PDF, also known as Version of record

[Link to publication from Aalborg University](#)

Citation for published version (APA):
Buus, A. A. Ø. (2021). *Investigation and Identification of Patients with Enhanced Care Needs after Knee Replacement Surgery*. Aalborg Universitetsforlag.

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**INVESTIGATION AND IDENTIFICATION
OF PATIENTS WITH ENHANCED CARE
NEEDS AFTER KNEE REPLACEMENT
SURGERY**

**BY
AMANDA AGNES ØSTERVIG BUUS**

DISSERTATION SUBMITTED 2021



AALBORG UNIVERSITY
DENMARK

INVESTIGATION AND IDENTIFICATION OF PATIENTS WITH ENHANCED CARE NEEDS AFTER KNEE REPLACEMENT SURGERY

by

Amanda Agnes Østervig Buus



AALBORG UNIVERSITY
DENMARK

Dissertation submitted

November 2021

Dissertation submitted: November 2021

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Department: Department of Clinical Medicine

ISSN (online): 2246-1302

ISBN (online): 978-87-7573-980-6

Published by:
Aalborg University Press
Kroghstræde 3
DK – 9220 Aalborg Ø
Phone: +45 99407140
aauf@forlag.aau.dk
forlag.aau.dk

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Printed in Denmark by Rosendahls, 2022



CV

Amanda Agnes Østervig Buus (born 1984) received a bachelor's degree in Nursing (BN) in 2008 from the University College of Northern Jutland, Aalborg, Denmark. Amanda has worked as a full-time nurse for two years at Aalborg University Hospital, Denmark. Her clinical experience as a nurse is in rheumatology and orthopaedics. In 2012, she completed a Master of Science (MSc) in Clinical Science and Technology from the Department of Health, Science and Technology, Aalborg University, Denmark. Afterwards, she took a position as a nursing specialist in the Surgical Department, Thy-Mors Hospital, North Denmark Region. In 2014, Amanda was enrolled as a PhD student in the Department of Clinical Medicine at Aalborg University while employed in the Clinic Hoved-Orto in the Department of Orthopaedic Surgery, Aalborg University Hospital. Her PhD study was supervised by Professor Ole K. Hejlesen and co-supervised by Associate Professor Britt Laugesen. Amanda was on maternity leave three times during her PhD study.

ENGLISH SUMMARY

Background

The accelerated care pathway, also known as ‘fast-track-surgery’, has become a well-established approach for patients undergoing knee replacement surgery. The concept aims to improve functional convalescence and minimise complications, enabling early discharge, within 2-3 days, after surgery. The care of patients is organised around viewing the patient as an active participant with increased responsibility for managing his or her own care and rehabilitation postoperatively. Information and guidance from health care professionals are therefore fundamental needs of the patients, as this will enable patients to manage their conditions and obtain the best possible postoperative health outcomes. However, patients report physical and psychosocial problems as well as difficulties in applying information and skills learned in the hospital to manage continued pain and functional disabilities after discharge. Health care professionals have also raised concerns that patients’ problems and care needs are not identified after discharge from the hospital, yet they lack tools to identify patients who are likely to have a challenging recovery and need enhanced care.

Aim

The overall aim of this thesis was to investigate the potential of identifying patients with enhanced care needs in the accelerated care pathway. This included identification and synthesis of patients’ pre- and post-operative experiences with information and analyses of the application of changes in patient-reported Oxford Knee Score (OKS) before and after surgery as a proxy measure to identify patients likely to have enhanced care needs.

Four studies were undertaken with the following study objectives:

- To identify and synthesise knowledge of how patients undergoing knee replacement surgery experience pre- and post-operative information provided by health care professionals.
- To identify the best predictors of patients with enhanced care needs following knee replacement surgery.
- To assess the potential of dividing the OKS into subscales for predicting clinically meaningful changes in pre- and postoperative pain and function by comparing two versions of extracting pain and function from the OKS
- To use traditional statistics and machine learning to develop prediction models that identify patients who are likely to have increased care needs related to managing pain and function following knee replacement surgery as described by the OKS function and pain subcomponents.

Methods

Study I was a systematic review and narrative synthesis that synthesised findings from 31 studies. *Study II* was a descriptive correlational study using the OKS as a proxy to identify predictors of patients with enhanced care needs following knee replacement surgery. *Study III* was a retrospective observational cohort study aiming to assess the potential of dividing the OKS into subscales for predicting clinically meaningful changes in pre- and post-operative pain and function. *Study IV* was a developmental study investigating whether machine learning models can be used to identify patients without clinically meaningful changes in pain and function who are likely to have enhanced care needs for managing pain and functional limitations after knee replacement surgery.

Results

Study I included 31 studies that were synthesised into five themes of patients' experiences with information provided by health care professionals: 1) Support in the decision to undergo surgery, 2) Confidence versus uncertainty in the preparation for surgery, 3) Prerequisites for feeling secure before discharge, 4) Struggling through rehabilitation at home, and 5) Unmet expectations and endeavours to accept realities. *Study II* suggested predictors of patients who are likely to have enhanced care needs. These characteristics included the presence of comorbidities and baseline OKS, anxiety/depression, and prior knee surgery. *Study III* indicated that it is reasonable to separate the OKS into a pain component and a functional component for predicting clinically meaningful changes in pre- and post-operative pain and function. *Study IV* showed acceptable model performance for predicting patients with enhanced care needs in managing pain and function, with an AUC of 0.73 for pain and an AUC of 0.77 for function.

Conclusion

This thesis presents novel ideas and perspectives for identifying patients with enhanced care needs in the accelerated care pathway. The research revealed how some patients experience inadequate postoperative improvements in pain and function after undergoing knee replacement surgery and lack adequate information and support from health care professionals to manage their conditions. These findings pointed to the importance of early identification of patients with enhanced care needs for managing pain and functional limitations. The developed prediction models in this thesis research seem promising for identifying patients with inadequate improvement in pain and function who are likely to have enhanced care needs. Further studies should be undertaken to refine and validate the prediction models before implementation in clinical care. This research is considered a first step towards developing future interventions targeted to the subset of patients with inadequate improvement in pain and function who are likely to have enhanced care needs.

DANSK RESUME

Baggrund

Den accelererede patientforløb, også kaldet fast-track-program, er blevet en veletableret tilgang til behandling og pleje af patienter, der gennemgår en knæalloplastikoperation. Konceptet har til formål at forbedre funktionel rekonvalescens og minimere komplikationer, hvilket har gjort det muligt at reducere indlæggelsestiden til omkring 2-3 dage. Udgangspunktet i patientforløbet er, at den enkelte patient ser sig selv som en medansvarlig og aktiv samarbejdspartner i egen behandling og rehabilitering. Information er derfor et vigtigt element i patientforløbet, der er afgørende for, at patienterne har den nødvendige viden til at håndtere deres situation og opnå de bedst mulige postoperative forbedringer. Imidlertid beretter patienterne om vanskeligheder med at anvende den information, de har modtaget fra sundhedsprofessionelle på hospitalet, og de oplever problemer med at håndtere vedvarende smerte og/eller funktionsnedsættelse efter udskrivelsen fra hospitalet. Sundhedsprofessionelle har også rejst bekymring over, at patienters problemer og behov ikke altid imødekommes efter udskrivelse fra hospitalet, men de mangler redskaber til at identificere de patienter, der har øget behov for støtte og pleje til at håndtere deres situation.

Formål

Det overordnede formål med denne ph.d.-afhandling var at undersøge muligheden for at identificere patienter med øget behov for støtte og pleje i det accelererede patientforløb. Det omfattede identificering og syntese af patienters præ- og postoperative oplevelser af information samt analyse af ændringer i den præ- og postoperative patientrapporterede Oxford Knee Score (OKS) som en metode til at identificere patienter med øget behov for støtte og pleje efter operationen.

Fire studier blev gennemført med følgende formål:

- At identificere og syntetisere den eksisterende viden om patienters oplevelse af præ- og postoperativ information fra sundhedsprofessionelle i forbindelse med knæalloplastikoperationer.
- At identificere de bedste faktorer til at prædiktere patienter med øget behov for støtte og pleje efter knæartroplastikoperationer.
- At vurdere potentialet i at opdele OKS i separate underskalaer til at prædiktere kliniske meningsfulde ændringer i smerte og funktion efter knæalloplastikoperationer.
- At anvende traditionelle statistiske metoder og maskinindlæringsmetoder til at udvikle prædiktionsmodeller til at identificere patienter med øget behov for støtte til at håndtere smerter og funktionsnedsættelse efter knæalloplastikoperationer.

Metode

Studie I var et systematisk review og narrativ syntese baseret på kvalitative og kvantitative forskningsartikler. *Studie II* var en deskriptiv korrelationsundersøgelse med anvendelse af ændringer i præ- og postoperativ OKS til at identificere de bedste faktorer til at prædiktere patienter med øget behov for øget støtte i forløbet efter deres knæalloplastik. *Studie III* var en retrospektiv observationskohorteundersøgelse med fokus på opdeling af OKS-instrumentet i underskalaer for at prædiktere forbedringer i præ- og postoperativ smerte og funktion separat. *Studie IV* var et proof-of-concept studie baseret på brugen af prædiktionsmodeller til tidlig identificering af de patienter, der ikke opnår kliniske meningsfulde forbedringer i smerte og/eller funktion efter deres knæalloplastikoperation.

Resultater

Studie I identificerede 31 forskningsartikler, der blev syntetiseret i fem temaer vedrørende patienters oplevelse af information fra sundhedsprofessionelle 1) støtte i beslutningen om at gennemgå operation, 2) selvtillid versus usikkerhed i forberedelsen op til operation, 3) forudsætninger for at føle sig tryk før udskrivelse, 4) udfordringer ved at håndtere rehabiliteringen derhjemme, og 5) uopfyldte forventninger og bestræbelser på at acceptere realiteterne. *Studie II* viste at de bedste faktorer til at identificere patienter med øget behov for støtte og pleje i patientforløbet er antallet af ko-morbiditeter, tilstedeværelse af diabetes, baseline OKS, angst/depression og tidligere operation i knæet. *Studie III* viste potentialet ved at opdele OKS-instrumentet i en smertekomponent og en funktionskomponent til prædiktering af klinisk meningsfulde forbedringer i henholdsvis smerte og funktion. *Studie IV* viste, at prædiktive modeller kan anvendes til tidlig identificering af patienter, der ikke opnår kliniske meningsfulde forbedringer i smerte og/eller funktion og som derved kan have gavn af øget støtte og pleje i patientforløbet.

Konklusion

Denne afhandling præsenterer nye ideer og perspektiver til at forbedre patientforløbet i forbindelse med knæalloplastikoperationer. Fundene viste, at mens nogle patienter klarer sig godt, så oplever andre vedvarende smerte og funktionsnedsættelse og har brug for mere støtte og pleje til at håndtere udfordringerne i forbindelse med operationen og den efterfølgende rehabilitering. Der er derfor behov for tidlig identificering af de patienter, der får problemer med vedvarende smerte og funktionsnedsættelse for at kunne lave en differentiering i den støtte, der tilbydes patienterne. Fundene viste også at anvendelse af prædiktionsmodeller ser ud til at kunne hjælpe sundhedsprofessionelle med tidligt at identificere de patienter, der får problemer med vedvarende smerte og funktionsnedsættelse efter operationen. Der bør imidlertid foretages yderligere undersøgelser for at validere prædiktionsmodellerne inden implementering i klinisk praksis.

PREFACE

This PhD thesis was carried out during my time as a PhD student enrolled in the Doctoral School in Medicine, Biomedical Science and Technology at Aalborg University, Denmark while employed at Clinic Hoved-Orto, Aalborg University Hospital, Denmark.

My initial interest and motivation for this work arose from my background as a nurse and my interest in the health care field. Before beginning my research, I met patients who were undergoing knee replacement surgery during different phases of the surgical care pathway. The patients described a complexity of experiences and challenges such as fears, insecurity, helplessness and despondency in their management of postoperative rehabilitation at home. Some of the patients also expressed how they would have benefitted from increased information and support from health care professionals postoperatively. The conversations with patients took place during my employment in Clinic Hoved-Orto before I was enrolled as a PhD student, which aroused my curiosity and inspired this work.

This thesis is organised into nine chapters with the following contents:

Chapters 1–2: These chapters present the introduction and background of the research topics, building the study rationale.

Chapter 3: This chapter presents the overall aim of the thesis and the four study objectives. The use of the terms ‘care needs’ and ‘information’ are explained to ensure clarity of the concepts. This was followed by a description of contextual details and ethical considerations of Studies II-IV.

Chapters 4–7: Each of these chapters summarises key aspects of methods and results of the four studies that were conducted as part of the thesis.

Chapter 8: This chapter brings together and discusses key research in the context of the existing literature and the overall aim of this research. This is followed by highlighting the strengths and limitations of the research. The chapter ends with a discussion of implications for practice and suggestions for future research.

Chapter 9: The final chapter concludes the thesis.

ACKNOWLEDGEMENTS

This thesis would not have been possible without innumerable people who made positive contributions to this exciting and challenging journey.

First and foremost, I would like to thank my supervisors during this project, Ole K. Hejlesen and Britt Laugesen. I am very thankful that you shared your expertise and ideas and provided me with constructive criticism throughout this research process. I also wish to express my gratitude for your encouragement and your continuous support. I have enjoyed all of our conversations and discussions, academic and personal, during my time as a PhD student.

I would also like to acknowledge and thank all my co-authors. I am very grateful for their collaboration and contribution: Charlotte Bjørnes provided valuable constructive criticism and professional feedback on the systematic review and narrative synthesis. Michael Falk Hvidberg has been a great help with technical assistance in the extraction and merging of patient data. Flemming Witt Udsen provided valuable help with statistics and machine learning. Mogens Laursen and Anders El-Galaly have, as orthopaedic surgeons, been a great help with the clinical aspects of this work.

Another group of people to whom I wish to express my gratitude are my colleagues and fellow PhD students in the Clinical Nursing Research Unit. Thank you for contributing to an inspiring and supportive network. I am grateful for all our discussions and being able to share challenges as well as accomplishments with you. I have truly missed the good company in the PhD office while working at home due to coronavirus restrictions.

I also extend my sincerest appreciation to Clinic Hoved-Orto at Aalborg University Hospital for paving the way for this exciting journey and for financing this PhD project. I thank you for providing me with this opportunity. Additionally, special thanks to all the research participants who completed the patient-reported outcome questionnaires through which they expressed their perceptions of their health conditions.

Last, but not least, I would like to express my greatest and warmest thanks to my family for stepping in and supporting me throughout this journey. In particular, very special thanks to Christian for his patience and love for me and our three girls. Finally, my deepest gratitude goes to my three wonderful girls, Benedicte, Clara and Ada, for providing me happy distractions outside of this research and for continuously reminding me of the joyfulness of life.

Amanda Buus, September 2021.

PUBLICATION LIST

THESIS PUBLICATIONS

The present thesis is based on four papers referred to by their Roman number (I-IV):

Paper I

Buus AAØ, Hejlesen OK, Bjørnes CD, Hejlesen OK, Laugesen B.
Experiences of pre- and postoperative information among patients undergoing knee arthroplasty: a systematic review and narrative synthesis.
Published in Disability and Rehabilitation (2019).
DOI: 10.1080/09638288.2019.1615997.

Paper II

Buus AAØ, Laugesen B Hvidberg MF, Anders E-G, Laursen M, Hejlesen OK.
Predictors of patients with enhanced care needs following total knee arthroplasty.
Manuscript submitted for publication in Orthopaedic Nursing (2021).

Paper III

Buus AAØ, Laugesen B, Hvidberg MF, Anders E-G, Laursen M, Hejlesen OK.
The potential of dividing the Oxford Knee Score in subscales for predicting clinically meaningful changes in pain and function of patients undergoing total knee arthroplasty.
Manuscript submitted for publication in International Journal of Orthopaedic and Trauma Nursing (2021).

Paper IV

Buus AAØ, Laugesen B Hvidberg MF, Anders E-G, Laursen M, Hejlesen OK.
Predicting patient-reported outcomes indicating enhanced care needs for managing function and pain in total knee arthroplasty patients: a development study.
Manuscript submitted for publication in Nursing Research (2021).

RELATED PUBLICATIONS

Contributions have been made to the following papers:

Journal papers

Andersen JD, Hangaard S, Buus AAØ, Laursen M, Hejlesen OK, El-Galaly A.
Development of a multivariable prediction model for early revision of total knee arthroplasty – the effect of including patient-reported outcome measures.
Published in Journal of Orthopaedics (2021).
DOI: 10.1016/j.jor.2021.03.001

Christiansen LK, Rasmussen AM, Mouritzen HS, Buus AAØ, Grønkaer M.
Quickly home again: patients' experiences of early discharge after minor stroke.
Published in Scandinavian Journal of Caring Sciences (2020).
DOI: 10.1111/scs.12937

Laursen SH, Buus AAØ, Jensen MH, Vestergaard P, Hejlesen OK.
Distribution volume assessment compartment modelling: theoretic phosphate kinetics in steady state hemodialys patients.
Published in The International Journal of Artificial Organs (2015).
DOI: 10.5301/ijao.5000449.

Conference papers

Laursen SH, Buus AAØ, Brandi L, Vestergaard P, Hejlesen OK.
A Decision Support Tool for Healthcare Professionals in the Management of Hyperphosphatemia in Hemodialysis.
Published in Studies in Health Technology and Informatics (2018).
DOI: 10.3233/978-1-61499-852-5-810.

Heiden S, Buus AAØ, Jensen MH, Hejlesen OK.
A diet management information and communication system to help chronic kidney patients cope with diet restrictions.
Published in Studies in Health Technology and Informatics (2013).
DOI: 10.3233/978-1-61499-289-9-543.

Buus A, Nyvang L, Heiden S, Pape-Haugaard L.
Quality assurance and effectiveness of the medication process through tablet computers?
Published in Studies in Health Technology and Informatics (2012).
DOI: 10.3233/978-1-61499-101-4-348.

ABBREVIATIONS

AUC	Area under the curve
CI	Confidence interval
DKR	Danish knee arthroplasty registry
EQ-5D	European quality of life five dimensions
IQR	Interquartile range
OKS	Oxford knee score
PRISMA	Preferred reporting items for systematic reviews and meta-analyses
PROM	Patient-reported outcome measures
R²	Coefficient of determination
RMSE	Root mean square error
SD	Standard deviation
STROBE	Strengthening the reporting of observational studies in epidemiology
TRIPOD	Transparent reporting of a multivariable prediction model for individual prognosis or diagnosis
VAS	Visual analogue scale

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CHAPTER 1. INTRODUCTION

The accelerated care pathway has become a well-established approach in the care of patients undergoing knee replacement surgery, and patients have become responsible for managing their own care and rehabilitation after increasingly shorter hospital stays (1–3). Health care professionals’ provision of appropriate information and guidance to support patients in managing their conditions, from preadmission counselling to discharge and beyond, is therefore crucial for meeting the care needs of patients undergoing knee replacement surgery (2–5). However, patients have reported that they encounter physical and psychosocial problems and experience unmet care needs (6–8). Patients have also reported difficulties in applying information and skills learned in the hospital to manage continued pain and functional disabilities at home (9–12). Health care professionals have similarly expressed concerns that patients’ problems and care needs are not always identified in a timely manner during rehabilitation after discharge (11,13). These circumstances may yield serious consequences for patients’ well-being and ability to manage their conditions, and it may hinder them in obtaining the best possible postoperative health outcomes (2,4,13). The premise of this thesis is that health care professionals’ ability to identify patients with enhanced care needs and provide information and guidance accordingly, are pivotal to increase patients’ knowledge and self-management skills important for obtaining better postoperative patient outcomes (2,4). However, health care professionals lack clinical tools to predict which patients will experience challenges in the management of their conditions due to inadequate postoperative recovery. The development of prediction models using patient-reported outcomes may help health care professionals identify patients undergoing knee replacement who are likely to have enhanced care needs for managing pain and functional disabilities.

In two stages, this thesis sought to investigate and predict patients with enhanced care needs in the accelerated care pathway. The first stage of the thesis (Study I) sought to understand how patients experience information provided by health care professionals to manage their conditions throughout the entire care pathway. The second stage of the thesis (studies II-IV) sought to develop potential solutions to the problems identified in Study I. Study II sought to identify the best preoperative predictors of patients who are likely to have enhanced care needs. Study III assessed the potential of subdividing the OKS into subcomponents for predicting clinically meaningful changes in pain and function separately. Finally, Study IV used traditional statistics and machine learning to develop prediction models for identifying patients without clinically meaningful changes in pain and function and, therefore, likely to have increased care needs for managing pain and function.

CHAPTER 2. BACKGROUND

This chapter presents the background and main problems underlying the thesis research. The background is divided into three sections. First, the epidemiological characteristics and the surgical procedure in knee replacement surgery are presented. Second, the concept and trajectory of the accelerated care pathway are outlined, followed by a description of patient information and care needs. The third section presents predictive modelling in health care and its use and possibilities in the care of patients undergoing knee replacement. Finally, a summary and overall rationale for the thesis are presented.

2.1. KNEE REPLACEMENT SURGERY

This section presents the demographics of patients and the surgical procedure of undergoing knee replacement surgery.

2.1.1. EPIDEMIOLOGICAL CHARACTERISTICS

Knee replacement surgery, also called knee arthroplasty surgery, is a frequently performed operation for people with advanced degenerative joint diseases, which are conditions resulting in pain, mobility limitations and reduced quality of life (14,15). Approximately 700,000 patients undergo knee replacement surgery annually in the United States (16), and approximately 8,000 patients have the procedure in Denmark (17). The annual volume of patients undergoing knee replacement surgery is expected to increase considerably worldwide due to demographic changes in the population and a rising prevalence of people with osteoarthritis (16,18,19).

The most common surgical indication is osteoarthritis, accounting for 84.9% of patients, yet the surgery is also offered to patients with rheumatoid arthritis, psoriatic arthritis and malignancies (20,21). Patients undergoing knee replacement surgery usually have severe pain and mobility problems making daily tasks difficult, e.g., they have problems walking, running, climbing stairs, and getting in and out of chairs and cars (21). More females (59%) than males have knee replacement surgery (17). The average age of patients undergoing surgery is 67 (22), and 22% are younger than 60 (17). The incidence of younger and more active patients undergoing the surgery has been increasing caused by improvements in implant materials and durability (19,23).

2.1.2 THE SURGICAL PROCEDURE

Knee replacement surgery is an invasive surgical procedure confirmed to be effective for relieving pain and restoring function (18,24). Surgery is considered for patients in whom conservative treatment, such as lifestyle modifications, analgesics and

exercises, is inadequate to maintain knee function and relieve pain (15,24). The procedure involves replacement of damaged bone and cartilage in a dysfunctional knee with an artificial joint (prosthesis) made of metal and plastic parts (24,25). There are two main types of knee replacement procedures that may be suitable depending on damage to the affected knee: total knee replacement and partial knee replacement. In total knee replacement, the entire joint is replaced with an artificial joint. In partial knee replacement, either the lateral compartment or the medial compartment of the knee joint is replaced with artificial parts (24,25). Both total knee replacement and partial knee replacement involve surgical insult to soft tissues, ligaments and surrounding muscles, yet partial knee replacement is often performed with a smaller incision (25,26). The expected improvement in pain and function is often not immediate but is achieved gradually within one year after surgery (25,27).

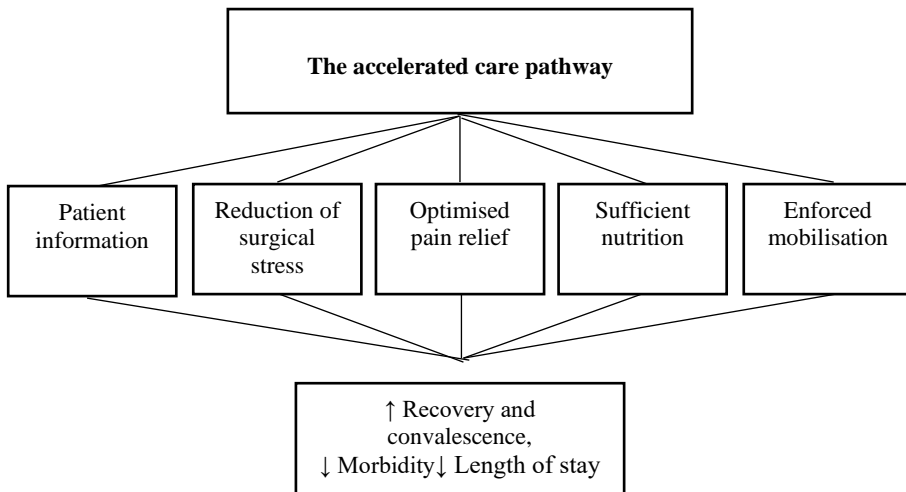
2.2. THE ACCELERATED CARE PATHWAY

This section describes the concept of the accelerated care pathway and provides an understanding of its organisation throughout the care pathway. The significance of patient information and challenges to identify patient care needs are outlined.

2.2.1. THE CONCEPT OF ACCELERATED SURGICAL CARE

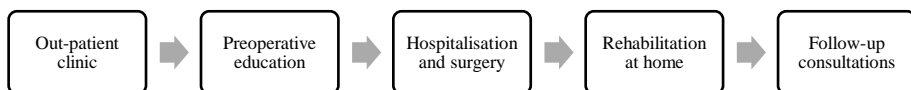
The accelerated care pathway, also known as fast-track surgery or enhanced recovery programs, has been adopted nationally and internationally for patients undergoing knee replacement surgery to reduce morbidity and enhance postoperative recovery and convalescence; secondary benefits include reductions in length of hospital stays and costs (28,29). The concept is based on multidisciplinary collaboration of health care professionals and standardised, evidence-based, multimodal principles of care consisting of five key elements: preoperative optimisation and information, reduction of surgical stress, optimised pain relief, sufficient nutrition and early mobilisation (Figure 1) (29–31). This includes, for example, preoperative information, minimally invasive surgical techniques, epidural or spinal anaesthetics instead of general anaesthetics, enhanced mobilisation, multimodal pain-relieving treatment and nausea prophylaxis (29,31). Health care professionals in hospitals providing treatment and care to patients include surgeons, anaesthetists, nurses, physiotherapists, occupational therapists and dieticians (3,29,32).

The accelerated care pathway has been found to be both feasible and safe for patients (33,34). However, patients experience a high prevalence of physical and psychological health problems following discharge (7,35,36), and there has been a discussion on whether the accelerated care pathway is appropriate for all patients, as some patients might need additional care resources to achieve optimal benefits after surgery, e.g., patients with comorbidities and advanced age (15,34,37–41).

Figure 1. The five key elements of the accelerated care pathway¹.

2.2.2. THE TRAJECTORY OF SURGICAL TREATMENT AND CARE

The accelerated care pathway begins with the patients' initial contact at the outpatient clinic and continues through preoperative education, hospitalisation, surgery, and rehabilitation at home followed by postoperative consultations with multidisciplinary health care professionals (3,33). The main phases of the accelerated care pathway are shown in Figure 2.

Figure 2. An outline of the phases in patients' trajectory of care.

Although knee replacement surgery is a major operation, the length of hospitalisation has declined in recent decades, from 10–14 days to approximately 2–3 days (33,42–49). This tendency seems to remain, and some go further, suggesting same-day admission and discharge of patients (39,50,51). Preoperative education is usually offered to patients and their relatives 1–4 weeks prior to the surgery and is organised in most departments as group sessions (33,43,52). Patients are most often admitted to

¹ The figure is modified from reference (30).

the hospital unit on the day of surgery (5,43,53). In most countries and hospitals, there are no rehabilitation facilities after undergoing knee replacement surgery, and patients are discharged directly to their homes (33,34). In most hospitals, rehabilitation after discharge has been moving to a home-based self-directed rehabilitation as the standard of care, and supervised rehabilitation by a physiotherapist is often only provided as needed (53–55). After hospitalisation, patients are typically seen for follow-up consultations by multidisciplinary health care professionals in the hospital, which are often scheduled approximately eight weeks and one year after the surgery (4,33,53,56).

2.2.3. PATIENT INFORMATION

Patient information is a crucial part of the provision of safe and effective care of patients undergoing knee replacement surgery to increase patient knowledge and encourage self-management to obtain the best possible postoperative outcomes (2,33,52,53). Information is provided to patients by health care professionals at all stages of the care pathway, from the first preoperative consultations, preoperative education, hospitalisation, and follow-up consultations (2,3,57). However, increasingly shorter hospital stays imply that health care professionals have reduced time to provide information to patients before discharge (2,3). As a consequence, it seems that some patients leave the hospital without adequate knowledge and skills to manage their conditions at home, e.g., physical limitations, rehabilitation exercises, possible complications, pain issues, and self-care activities (3,8,12,57).

Preoperative multidisciplinary education is provided to patients and their families to prepare them for surgery, hospitalisation, discharge, and rehabilitation at home, including pain management and physical exercise training (2,52). Although preoperative education often receives positive evaluations by patients, some patients describe being unable to transform the information into practical skills after returning home (9–11). The effectiveness of the preoperative education offered to patients has been debated, as evidence has shown that there are no benefits in terms of improved postoperative outcomes related to function, pain, complications and length of stay (58–60). These findings are also in accordance with studies showing no differences in patient satisfaction between patients who attend preoperative education and those who do not (2,61). On account of these findings, it might not only be the information provided during preoperative education that matters to patients but also the sum of information provided to patients by health care professionals during the entire surgical care pathway (2,61,62).

The patients' readiness to take in new information, as well as the content and amount of information the patients need, seems to vary throughout the various phases of the care pathway (13). Information given to patients at one stage may influence patients' experiences and needs in subsequent stages in the care pathway (62,63). Although studies of patients' experiences with information exist in separate periods (e.g., during

preoperative education and at admission before discharge), little is known about patients' experiences of information provided by health care professionals throughout the entire care pathway (62). Another important aspect is that information given to patients is mainly based on what health care professionals think patients ought to know rather than on patients' experiences and needs (64). It has been shown that information provided to patients is most effective when it is tailored to their specific characteristics and individual care needs (65).

The undiscovered issues mentioned above raise questions as to how patients experience information provided by health care professionals on how to manage their conditions throughout the entire surgical care pathway, i.e., from the preoperative stage through hospitalisation and postoperative rehabilitation at home.

2.2.4. UNMET CARE NEEDS IN THE ACCELERATED CARE PATHWAY

The care needs of patients undergoing knee replacement are often complex and multidimensional (3,8,43,66). Previous studies exploring patients' experiences of care have shown that undergoing knee replacement surgery remains associated with several physical and psychosocial postoperative problems and unmet care needs (6,13,36,67). Patients experience physical and psychosocial problems and unmet needs related to physical activity and self-care deficits, such as oedema, pain, infection, distress, hopelessness, bowel function, sleep disturbances, and unmet expectations for postoperative recovery (68,69). In particular, patients have reported that they experience challenges in managing pain and functional limitations in rehabilitation at home (8,70–72). This can have serious consequences for patients; for example, insufficient support for coping with pain management can cause inadequacies in patients' functional capacity and may negatively influence the execution of postoperative rehabilitation exercises, which are important for achieving long-term outcomes after surgery (63,73,74). Other long-term consequences of unmet care needs include the development of stress, anxiety and depression that can have serious consequences for patients' well-being and general health (63,75).

Health care professionals in hospitals providing care to this patient population have also pointed out that patients' problems and care needs in rehabilitation at home are not always identified (11,13). Holland et al. (69) have problematised that patients' challenges in their home environments are often not appropriately addressed because they are not identified by health care professionals in the hospital before discharge. This is of major concern in clinical care, as health care professionals play an important role in supporting patients in executing appropriate health behaviours important for the success of knee replacement surgery (75). A study has shown that as many as 45.6% of patients undergoing knee replacement surgery have pain levels above the recommended thresholds at home, and 69.8% of the patients do not perform postoperative exercises as recommended (7). The chances of a successful treatment outcome for a patient who is adherent is substantially higher than for a patient with

low adherence; however, adherence to treatment recommendations requires the patient to have appropriate knowledge to promote his or her own health (76). The presence of these deviations from the recommendations also suggests the occurrence of unidentified problems and unmet care needs of patients undergoing knee replacement surgery (69). However, there are currently no clinical tools available to help health care professionals predict which patients may have challenging recoveries and need enhanced care (13,15,69).

The abovementioned challenges may be addressed by developing prediction models to assist health care professionals in the hospital in identifying patients struggling with continuing pain and functional limitations after surgery (15,77). Hence, the development of a prediction model may therefore be a first step towards identifying patients who might benefit from enhanced levels of care in the accelerated care pathway.

2.3. PREDICTIVE MODELLING IN HEALTH CARE

This section presents existing predictive modelling tools within knee replacement surgery and within nursing care and sheds light on the possibilities of using patient-reported outcome measures (PROMs) in predictive modelling to identify patients struggling with continued pain and functional limitations who are likely to have enhanced care needs for managing their conditions after knee replacement surgery.

2.3.1. PREDICTIVE MODELLING IN KNEE REPLACEMENT SURGERY

Predictive modelling has been successfully utilised to make predictions about future events, activities, behaviours or clinical outcomes for patients in various populations (78–80). The increased accessibility to routinely collected clinical data and a growing field of advanced predictive analytics, traditional statistical and machine learning, support the utility of predictive modelling in a health care setting (81). The main aim of predictive modelling in health care is to use a multivariate set of predictors to anticipate outcomes for individual patients, allowing creation of personalised treatment and care plans tailored to patients' individual needs (78). Predictive modelling has the potential to offer health care professionals assistance in clinical decision-making to improve patient care and obtain improved health outcomes (78).

Predictive modelling studies in knee replacement surgery focus on overall treatment success or the risk of adverse events to assist surgeons in selecting patients suitable for undergoing knee replacement surgery or to determine surgical strategy (82). Studies of predictive modelling within knee replacement surgery cover a wide range of contents for predicting clinical events and outcomes, such as length of stay (83), readmission (84), morbidity (85), revision surgery (86) satisfaction (87) and various PROMs for assessing outcomes from the patient perspective, including the Western

Ontario and McMaster Universities OA Index (WOMAC) (88), Knee injury Osteoarthritis Outcome Score (KOOS) (84,89) and the OKS (90–93).

2.3.2. PREDICTIVE MODELLING IN NURSING CARE

Predictive modelling may also represent a way to predict patient outcomes that can inform clinical reasoning and care planning in nursing care (79,94). However, the use of predictive modelling is only emerging in the field of nursing research for predicting patient care outcomes (94,95). Predictive modelling within nursing care does not intend to identify patients who are suitable for receiving a given treatment, e.g., for undergoing knee replacement surgery. Rather, it intends to identify patients who have been selected for surgery as potential beneficiaries of enhanced support and care resources (94,96). There are currently no easily adoptable measures to identify patients who will need enhanced care; therefore, previous studies have used various proxy measures to identify such patients (95–100). Proxy measures that are correlated to the outcome of interest can appropriately be used when direct measures of the outcomes are unavailable (97). For example, previous studies predicting outcomes relevant in nursing care have sought to identify patients' care needs using various proxies concerning a patient's health, such as activities of daily living (ADL), to predict unmet social care needs (95), discharge destination and need for care assistance to predict patients' care needs in primary care (98), prediction of functional loss among patients with fragile hip fractures (99), prediction of risk of mortality within 30 days for identifying palliative care needs (100) and prediction of mortality for identifying homebound elderly individuals in need of a focused nursing assessment (96).

2.3.3. MEASURES FOR IDENTIFYING PATIENTS WITH ENHANCED CARE NEEDS

There are currently no validated instruments for identifying and measuring potential enhanced care needs in patients undergoing knee replacement surgery. The challenge in this thesis was therefore to identify appropriate proxies to be used to identify patients who are likely to have enhanced care needs. PROMs have been implemented in health care aimed at providing patient-centred care (89,101). PROMs have become expansively applied in health care to incorporate patients' experiences in treatment and care (102,103). The use of PROMs have great potential to be applied as both a screening and dialogue tool in patient care (104,105). PROMs capture information relevant to patients, which is often related to what caused them to seek care in the first place (103). The opportunity to use PROMs to identify patients' care needs in clinical practice has already been proposed for patients with other conditions (103,106,107). Hence, PROMs may appropriately be used as a proxy measure for identifying patients who may need enhanced care after knee replacement surgery.

The patient-reported OKS is a condition-specific PROM consisting of 12 questions (items) reflecting a patient's perceptions of his or her health status based on challenges with pain and function in daily activities before and after undergoing knee replacement surgery (102). The use of the OKS has been increasing in popularity and it has been highlighted that the use of the score offer a potential to improve continuity of care in clinical practice (108,109). The OKS may reasonably be used as a proxy for identifying patients on a challenging path to recovery by identifying those who are not reaching clinically meaningful improvement and might benefit from enhanced information and guidance to manage their conditions following knee replacement surgery. Therefore, predicting patients' self-perceived change in pre- and postoperative pain and function measured with the OKS might be a reasonable approximation for identifying patients likely to have enhanced care needs because it identifies patients' recovery challenges related to function and pain based on their starting point (110). Patients gradually improve within one year following surgery (27), yet the early status of OKS has been shown to be correlated with long-term outcomes (111).

Studies of existing models predicting the OKS have sought to predict the overall summary OKS, including all 12 questions of pain and function in a combined outcome score, rather than predicting outcomes related to pain and function in separate scores (90–93). However, a patient's improvements in pain may disguise insufficient improvements in function (or even a worsening of function), which may not necessarily be distinguished by these prediction models. There appears to be clinical reasoning in subtracting separate questions of pain and function from the OKS into an 'OKS pain component' and an 'OKS function component' (26,108,109,112). Although authors in previous publications have extracted questions of pain and function separately from the OKS, it remains unclear which of the 12 questions should be allocated to the pain component and the function component (26,108,112–117). For example, some of the authors in previous studies assigned seven questions to the pain component and five questions to the function component (108,115–117), whereas others assigned five questions to the pain component and seven questions to the function component (26,112–114). In addition, most previous models have sought to predict absolute postoperative outcome scores instead of predicting whether a patient can achieve a clinically meaningful improvement between pre- and post-operative scores (90,92). It has been claimed that pre- and post-operative improvements in pain and function are a better indication of a patient's perceptions of care needs and outcomes, as the main goal of surgery is often to improve health conditions rather than cure all symptoms (118,119). Another angle is that most of the previous studies using predictive modelling approaches have used traditional statistical methods (linear and logistic regression), and only a few have used newer machine learning methods (91). However, machine learning approaches are known to be able to capture nonlinear relations and interactions and have often delivered better performance compared to more traditional statistical approaches, e.g., linear and nonlinear methods (120). Although traditional statistical models are typically more

transparent, which makes them attractive in clinical care, machine learning models might be better at providing accurate predictions of future patient outcomes (120).

2.4. SUMMARY AND RATIONALE FOR THE RESEARCH

The evidence presented in this chapter calls for alternative approaches to improve the care of patients undergoing knee replacement surgery. It has been outlined that the length of hospitalisation has been markedly reduced, and patients have to take greater responsibility for their own care after undergoing knee replacement surgery. Although shorter hospitalisations are shown to be safe, patients often face various challenges in the management of rehabilitation at home. Health care professionals in hospitals have also raised concerns that patients' care needs are not always identified in a timely manner.

The premise of this thesis is that appropriate information and guidance from health care professionals is a fundamental care need of patients undergoing knee replacement surgery. There is clinical consensus that patients need adequate information from health care professionals to participate in their own treatment and care, which is vital for obtaining the desired postoperative health outcomes. Although knowledge exists about how patients experience information in separate phases of the care pathway, there is a paucity in research about how patients experience information provided by health care professionals to manage their conditions throughout the entire surgical care pathway. This knowledge may assist health care professionals in improving continuity of care and accommodating patients' care needs throughout the care pathway.

Health care professionals lack tools with which to identify patients who may face challenging recoveries and need enhanced care to manage rehabilitation at home following surgery. Predictive modelling approaches may be a potential solution for the identification of patients with inadequate postoperative improvements who are struggling to manage their conditions. The development of prediction models using the patient-reported OKS for predicting pre- and post-operative changes in pain and function might, therefore, be a first step towards identifying individual patients with inadequate improvement who are likely to have enhanced care needs for managing challenges with pain and functional limitations.

The terms 'care needs' and 'information' require further explanation with respect to their use and meaning within the context of this thesis, which will be provided in Chapter 3.

CHAPTER 3. OVERALL AIM, STUDY OBJECTIVES AND OVERVIEW OF THESIS STUDIES

In this chapter, the overall aim of the thesis will be outlined, followed by the specific research objectives of studies I-IV. This is followed by a short clarification of how the terms 'care needs' and 'information' are conceptualised and how they are interrelated in this PhD thesis. Finally, the chapter presents contextual details and ethical considerations in studies II-IV.

3.1. AIM AND OBJECTIVES

The overall aim of this thesis was to investigate the potential to identify patients with enhanced care needs. This included identification and synthesis of patients' pre- and post-operative experiences with information and analyses of the application of changes in patient-reported OKS before and after surgery as a proxy measure to identify patients likely to have enhanced care needs. The premise of this research is that information is a fundamental care need and an important determinant for patients' ability to manage their conditions and achieve improved health outcomes following knee replacement surgery. Furthermore, the patients' self-reported changes in the OKS were considered a suitable and reasonable proxy for identifying patients who were likely to have enhanced care needs.

The four study objectives were as follows:

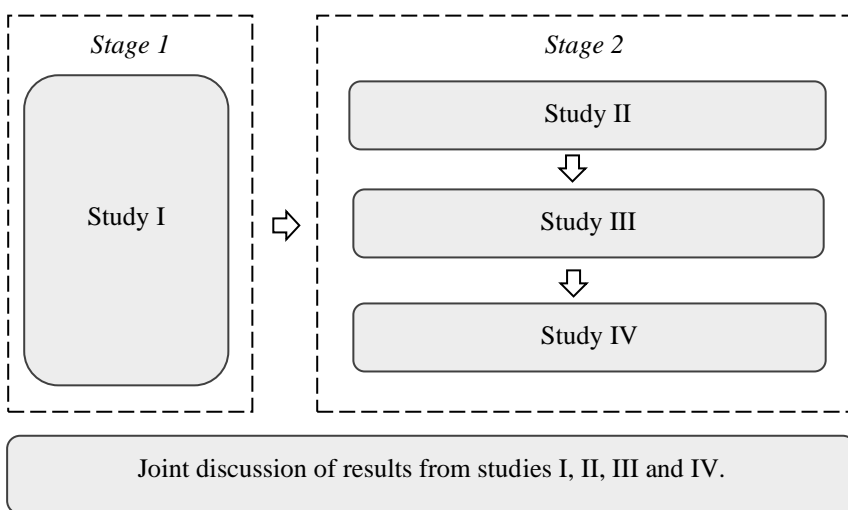
- The objective of Study I was to identify and synthesise knowledge of how patients undergoing knee replacement surgery experience pre- and post-operative information provided by health care professionals.
- The objective of Study II was to identify the best predictors of patients with enhanced care needs following total knee replacement surgery.
- The objective of Study III was to assess the potential of dividing the OKS into subscales for predicting clinically meaningful changes in pre- and postoperative pain and function by comparing two different versions of extracting pain and function from the OKS.
- The objective of Study IV was to use traditional statistics and machine learning to develop prediction models that identify patients who are likely to have increased care needs related to managing pain and function following

knee replacement surgery as described by the OKS function and pain subcomponents.

3.2. OVERVIEW OF CONNECTIONS BETWEEN THESIS STUDIES

This thesis research consisted of two stages, including four studies. The first stage consisted of Study I, which identified problems in clinical care and generated insights that were the basis for initiating the studies in the second stage of the thesis. In this way, studies in the second stage sought to provide solutions to the problems identified in Study I. Figure 3 illustrates how the studies are linked to each other and that previous studies either directly or indirectly informed research objectives and methods in subsequent studies. For example, insights generated in the process of conducting Study II contributed to the ideas of separating the OKS into a pain component and a function component and defining clinically meaningful threshold values using an anchor-based method in Study III. In addition, Study III informed Study IV by suggesting threshold values for predicting clinically meaningful changes in pain and function. Thus, findings from each of the studies complemented each other and contributed to answering the overall thesis aim.

Figure 3. Illustration of how the studies are linked as part of the thesis research.



3.3. DEFINITIONS

The understanding and use of the terms ‘care needs’ and ‘information’ are explained to ensure clarity about the concepts being used.

Care needs

The care needs of a patient are often complex and multidimensional, including an interdependence of physical, psychosocial, and relational needs of care (66). Examples of a patient’s *physical care needs* are personal cleansing, dressing, mobility, comfort (e.g., pain management) and safety (e.g., risk assessment and minimising complications). Examples of a patient’s *psychosocial care needs* are information, education, patient involvement, and having one’s values respected and considered. Examples of a patient’s *relational care needs* can be a need for someone to actively listen, help to cope with a new situation, and aid in setting, achieving, and evaluating the progression of goals (66). Unmet care needs are defined as the needs for treatment and care that patients identify as important but unsatisfied because they are either delayed or omitted (121). This thesis focuses on the development of predictive models that identify patients who are likely to have enhanced physical care needs related to pain and functional limitations rather than models that identify patients with all kinds of care needs that may emerge throughout the care pathway. Although challenges with pain and function at first seem to belong to a patient’s physical care needs, they may also have psychosocial and relational care needs that need to be considered in supporting their management of challenges with pain and functional limitations.

Information

As described above, information is considered a fundamental care need of patients undergoing knee replacement surgery. Information has been described as synonymous with concepts such as knowledge, understanding, education, instruction, communication, and meaning (122). Krikelas (123) described information as a “*stimulus that affects one’s certainty*”, which fits well within the context of this thesis given the uncertainty many patients experience while undergoing knee replacement surgery. Dervin goes further and describes information as a “*tool that is valuable and useful to people in their attempts to cope with their lives*”, which also agrees well with the underlying perception in this thesis that information is vital to reduce patient uncertainty and to assist them in managing their conditions after surgery.

3.4. STUDY CONTEXT AND ETHICAL CONSIDERATIONS

Patients in Studies II-IV were recruited from the Department of Orthopaedic Surgery, Aalborg University Hospital, Denmark. Prospectively collected data (PROM, patient characteristics and surgical information) were retrieved from the Danish Knee

Arthroplasty Registry (DKR) and an administrative database (Jointbase) at the hospital.

As standard care, patients in the hospital undergoing knee replacement surgery attend preoperative education approximately two weeks before admission, a session led by an orthopaedic ward nurse, a nurse anaesthetist and a physiotherapist. Most patients are admitted on the day of surgery, and they are mobilised on the day of surgery. Follow-up consultations are scheduled to occur approximately two months (physiotherapist) and 12 months (orthopaedic nurse) postoperatively. The patients are provided with a self-directed home exercise program (standard) or receive outpatient therapy directed by a physiotherapist (only if needed).

Ethical concerns were considered throughout the research and data collection process. All patients provided informed consent before data collection and were informed about the right to withdraw from data collection and analysis without consequences. For the purpose of confidentiality and anonymity, person identifiers were removed from the dataset during the data management and analysis process.

The thesis received approval from the Danish Data Protection Agency under the North Jutland Region's (Danish: Region Nordjylland) shared notification of health science research (Journal ID: 2008-58-0028, Project ID: 2018-42) (Appendix A).

CHAPTER 4. STUDY I

This chapter summarises the work conducted in the paper entitled “*Experiences of pre- and postoperative information among patients undergoing knee arthroplasty: a systematic review and narrative synthesis*” accepted for publication in *Disability and Rehabilitation* (2019).

4.1. METHODS

Study design

Study I was a systematic review and narrative synthesis adapting the guidelines on the conduct of narrative synthesis in systematic reviews by Popay et al. (124). These guidelines aimed to provide an approach for improving the transparency and trustworthiness of narrative evidence synthesis in clinical practice (124). The approach was chosen because it applies a textual approach for synthesis and is equally suitable for the synthesis of data from both qualitative and quantitative studies (124). The Preferred Reporting Items for Systematic reviews and Meta-Analyses guidelines (PRISMA) was adhered to for reporting the review (125).

Data collection

Systematic searches for relevant primary peer-reviewed studies were conducted with a research librarian and included studies published between January 2005 and December 2018. The searches were executed in CINAHL, MEDLINE, EMBASE, and PsycINFO. Search terms were organised in three blocks by using the PICO mnemonic for questions about experiences (126). Search terms in various combinations were adapted to functions and indexing terms in each database. An example of the search strategy in MEDLINE is illustrated in Appendix B.

Study selection

The inclusion criteria were primary peer-reviewed studies that included (1) adult patients ≥ 18 years, (2) patients who were undergoing or had undergone elective knee replacement surgery within the last 12 months, (3) patients’ experiences with information provided by health care professionals in the entire pre- and post-operative care pathway (including patient education, contacts in outpatient clinics, inpatient admissions, and while rehabilitating at home), (4) publications in English, Swedish, Norwegian, or Danish, and (4) publications between January 2005 and the end of 2018 to identify studies relevant to current clinical practice.

Studies with the following criteria were excluded: (1) studies with a mixed cohort of patients (e.g., patients undergoing hip and knee replacement) where findings were not distinguishable between patient groups, (2) studies solely concerning patients' experiences of conservative treatment methods, the period of waiting for knee replacement surgery and the intraoperative period, and (3) intervention studies.

Narrative synthesis process

The narrative synthesis process comprised three iterative stages with associated tools and techniques: 1) developing a preliminary synthesis of findings of the studies, 2) exploring relationships between and within studies, and 3) assessing the robustness of the synthesis (critical appraisal) (124). Although the three applied elements are described sequentially, the analysis was conducted in an iterative way (124). Table 1 lists tools and techniques applied in each stage of the synthesis process. More details are available in Paper I (72).

Table 1. The three stages and applied tools and techniques for narrative synthesis.

Stages	Tools and techniques
Developing a preliminary synthesis	<i>Textual descriptions of studies</i> <i>Tabulation of extracted data</i> <i>Developing synthesised themes</i>
Exploring relationships in data	<i>Identification of moderator variables/subgroup analysis</i> <i>Conceptual mapping</i>
Assessing the robustness of the synthesis	<i>The weight of evidence approach</i> <i>Critical appraisal of methodological quality</i>

4.2. RESULTS

Description of the studies included

A total of 31 studies concerning how patients undergoing knee replacement experience pre- and post-operative information provided by health care professionals

were included in the study. A presentation of the included studies can be found in Paper I. The process of study selection is illustrated in Table 2².

Table 2. Process of study selection.

Process of study selection	Number of records
Records identified through databases	6972
Records identified through other sources	3
Records after duplicates were removed	4621
Full-text papers considered for eligibility	93
Papers included in the synthesis	31

Synthesised themes

Study 1 resulted in five synthesised themes: 1) support in the decision to undergo surgery, 2) confidence versus uncertainty in the preparation for surgery, 3) prerequisites for feeling secure before discharge, 4) struggling through rehabilitation at home, and 5) unmet expectations and endeavouring to accept realities (72). Table 3 provides an overview of the synthesised themes and subthemes³.

Support in the decision to undergo surgery

This theme showed that information given in the preoperative contact in the outpatient setting was crucial for patients to feel supported and involved in the decision to undergo surgery. Most patients considered it important to be provided information to take part in an active role in the decision process. Health care professionals who were listening to patients' concerns decreased patients' feelings of uncertainty in the decision to undergo surgery. Patients also expressed deficiencies in the dialogue with health care professionals, which were described as one-way, and there was a lack of opportunity to have their questions answered. The consequences of these deficiencies included unclear expectations and decisional conflicts before undergoing surgery.

² Table 2 is an extract of Figure 1 in Paper I.

³ Table 3 is an extract of Table 2 in Paper I.

Table 3. Synthesised themes and sub-themes.

Themes	Sub-themes
Support in the decision to undergo surgery	<i>Roles and communication</i> <i>Decisional conflicts</i>
Confidence versus uncertainty in the preparation for surgery	<i>Clarifying the unknown</i> <i>Information barriers</i>
Prerequisites for feeling secure before discharge	<i>Feeling confident and reassured</i> <i>Accelerated care as a challenge to individual care</i>
Struggling through rehabilitation at home	<i>Unexpected challenges</i> <i>Trial and error at home</i> <i>Accessibility to health care professional</i>
Unmet expectations and endeavouring to accept realities	<i>An unexpected condition</i> <i>Accepting reality or resignation</i>

Confidence versus uncertainty in the preparation for surgery

Preoperative education in addition to written information was generally valued, as it increased patient understanding and confidence in preparation for the surgery. The information provided enabled patients to know what to expect during hospitalisation and rehabilitation, and they had the opportunity to have questions answered. However, expectations for information were not always fulfilled, and patients claimed that information was often not tailored to their perceived problems and needs. Patients also described to have difficulties taking in and understanding information provided in preoperative education sessions. These difficulties appeared more pronounced for patients undergoing knee replacement surgery for the first time. Although comprehensive and detailed information was valued, some patients seemed to feel that too much information was frightening and exacerbated difficulties in comprehending new information.

Prerequisites for feeling secure before discharge

This theme showed how information and dialogue with health care professionals were prerequisites for feeling secure before discharge from the hospital. Although some patients felt they were well prepared before being discharged home, others described the prerequisites for feeling safe before discharge were not achieved. Patients' confidence in being discharged home increased when they were provided thorough explanations and instructions. Insecurity also decreased when information given previously was repeated before discharge. Patients did not always feel prepared for exhaustion after the surgery, and postoperative health problems such as pain, nausea and exhaustion could hinder patients' ability to take in information during the hospital stay.

Struggling through rehabilitation at home

This theme illustrated how some patients required additional help to apply knowledge and skills learned during preoperative education hospitalisation in the home setting. Patients described that unexpected challenges arose at home, and they had not foreseen the consequences of surgery on their physical and emotional well-being, which made the early postoperative period hard to manage. Patients were particularly unsure of how to manage pain, what physical symptoms to expect, and some were afraid of doing harm to the prosthesis. Correspondingly, a sense of frustration and helplessness occurred, and some even discontinued their rehabilitation exercises. Patients faced difficulties contacting health care professionals as they did not know whom to contact or they felt it was not appropriate to do so. Nevertheless, patients requested additional information and guidance from health care professionals after discharge from the hospital for managing pain and function, which was considered important to reduce stress and obtain a better recovery.

Unmet expectations and endeavouring to accept realities

This theme covers how some patients struggled with unmet expectations and continued to be immobile and suffer pain in the long-term following surgery. While some of these patients contented themselves with a partial return to their daily activities, others were discouraged and even regretted that they had undergone the surgery. Patients did not always feel that health care professionals acknowledged their problems and addressed emotional cues in follow-up consultations. Some patients ended up feeling guilty and blamed themselves for not achieving surgical goals. The consequences of unmet expectations entailed emotional difficulties such as disappointment and depression.

4.3. CONCLUSION

This study provided insights into the importance of information from health care professionals to assist patients in the management of their conditions through the accelerated care pathway. Although some patients undergoing knee replacement surgery have positive experiences with information received from health care professionals, other patients experience major challenges in the recovery phase and need enhanced information and guidance to manage their conditions. In particular, the patients struggled to manage continued pain and functional limitations resulting in uncertainty and unmet expectations. These findings underpinned the need to identify patients who are struggling to manage continued pain and functional limitations and to assist them in the management of their conditions. This seems vital for improving patients' experiences of care and to achieve improved outcomes following surgery.

CHAPTER 5. STUDY II

This chapter summarises the work conducted in the paper entitled “*Predictors of patients with enhanced care needs following total knee arthroplasty*” submitted for publication in Orthopaedic Nursing (2021).

5.1. METHODS

Research design

Study II was conducted as a descriptive correlational study using a consecutive collection of routinely sampled data from a knee replacement database in the Department of Orthopaedic Surgery, Aalborg University Hospital, Denmark. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist for reporting cohort studies was used to report the study (127).

Study population

Patients scheduled for knee replacement surgery from February 2015 through December 2016 in the Department of Orthopaedic Surgery, Aalborg University Hospital, who met the inclusion/exclusion criteria were enrolled in the study (Table 4).

Table 4. Inclusion/exclusion criteria.

Inclusion criteria	Exclusion criteria
Patients undergoing elective, primary knee replacement surgery.	Patients who did not complete PROM questionnaires within 3 months prior to surgery and at least one year after the surgery.
Patients ≥ 18 years of age at the time of surgery.	For patients who received surgery for both knees during the study period, the second surgery's data were excluded.
Patients who consented to complete PROM questionnaires before and after surgery.	

Outcome measures

Patient-reported changes in the OKS⁴ (Appendix C), from baseline to the one-year follow-up, were used as a quantitative proxy for predicting patients with enhanced care needs (128). The primary outcome was dichotomized to whether the patients achieved an improvement in the OKS ≤ 9.6 (poor and moderate improvement), indicating that a higher level of care was needed in addition to standard care ('higher care needs'). The secondary outcome was dichotomized to whether the patients achieved an improvement in the OKS < 2.88 (poor improvement), indicating that an intensive level of care was needed ('intensive care needs'). The two threshold values were defined by an expert group within the hospital using the Delphi method (129,130).

Predictor variables

Nineteen potential predictor variables were included for analysis (Table 6).

Statistical analysis

For descriptive statistics of baseline patient characteristics, continuous variables were presented as the mean (\pm standard deviation) and categorical variables were presented as numbers (percentages).

The best predictors of patients with higher care needs and intensive care needs care needs were examined by multiple logistic regression. Logistic regression is appropriate for analysing associations between a dichotomous dependent outcome variable and continuous/categorical independent predictors (131). Logistic regression predicts the odds of membership in the outcome category (1 value) compared to the reference category (0 value) based on the independent variables (predictors) (131). For selecting independent variables, forward selection was applied to all predictors with $p < 0.25$ identified in the initial simple regression analysis (132). Metrics for performance evaluation included 1) the omnibus test of model coefficients using the chi-square (χ^2) test was used as a measure of the overall model fit to evaluate the final model over the baseline model; and 2) Nagelkerke's R^2 , a pseudo R^2 value, was provided as an indication of the amount of variation in the outcome explained by the model (133). In addition, the log odds ratios, odds ratios, 95% confidence intervals and p-values were calculated.

The statistical level of significance was set at $p < 0.05$, and all analyses were performed using IBM SPSS 25.0 statistical software.

⁴ (0–48 scale; 48 = best score/least problems).

5.2. RESULTS

Characteristics of included patients

In this study, 201 patients were included for analysis. The mean age was approximately 67 years, and most patients were females (55.2%). There were 129 patients who presented with comorbidities, while 72 patients presented with no comorbidities. Baseline study sample characteristics are shown in Table 5⁵.

Table 5. Baseline study sample characteristics.

Variables	Patients (N = 201)
Age at surgery, <i>mean</i> (SD)	66.8 (9.3)
Females, <i>n</i> (%)	111 (55.2%)
Body mass index, <i>mean</i> (SD)	29.9(5.5)
Marital status, <i>n</i> (%)	
Married	150 (74.6%)
Unmarried	51 (25.4%)
Comorbidities, <i>n</i> (%)	
0	72 (35.8%)
1–2	105 (52.2%)
3+	24 (12%)
Presence of diabetes mellitus, <i>n</i> (%)	57 (28.4%)
Previous surgery (same knee), <i>n</i> (%)	47 (23.4%)
Length of stay, <i>mean</i> (SD)	1.5 (.98)
Preoperative pain (0–100 scale), <i>mean</i> (SD)	
VAS (rest)	48.1 (24.0)
VAS (activity)	69.6 (19.7)
EQ VAS (0-100 scale), preoperative, <i>mean</i> (SD)	60.0 (21.0)
EQ-5D summary index, preoperative, <i>mean</i> (SD)	0.62 (.2)
OKS, preoperative, <i>mean</i> (SD)	20.9 (5.9)

⁵ Table 5 is an extract of Table 2 in Paper II.

Simple regression for identification of possible predictor variables

The simple regression analysis revealed ten potential predictors of patients with higher and intensive care needs (variables with a p value < 0.25) (Table 6)⁶.

Table 6. Simple regression analysis for identifying possible predictor variables.

Predictors	Intensive care needs		Higher care needs	
	B	OR (95% CI)	B	OR (95% CI)
Gender	0.45	1.57 (0.41–6.04)	-0.04	0.96 (0.48–1.91)
Age	-0.00	1.00 (0.93–1.07)	-0.01	1.00 (0.96–1.03)
Body mass index	0.07	1.07 (0.96–1.19)*	0.03	1.03 (0.97–1.09)
Marital status	-0.18	1.20 (0.24–5.97)	-0.07	0.96 (0.42–2.08)
VAS pain (activity)	-0.02	0.98 (0.95–1.01)*	-0.02	0.98 (0.96–0.99)*
VAS pain (rest)	-0.01	0.99 (0.96–1.02)	-0.01	0.99 (0.98–1.01)
Prior same knee surgery	1.02	2.77 (0.71–10.78)*	0.07	1.07 (0.48–2.39)
Number of comorbidities	0.51	1.66 (1.00–2.75)*	0.32	1.37 (1.03–1.83)*
Diabetes mellitus	1.19	3.28 (0.85–12.68)*	1.12	3.06 (1.50–6.23)*
EQ-5D (index score)	1.35	3.84 (0.04–407.9)	1.63	5.11 (0.49–53.91)*
EQ-5D (mobility)	-0.32	0.73 (0.09–6.19)	-1.13	0.32 (0.12–0.91)*
EQ-5D (self-care)	-0.31	0.73 (0.15–3.63)	-0.39	0.68 (0.30–1.53)
EQ-5D usual activities	-1.06	0.35 (0.04–3.13)	-1.07	0.34 (0.10–1.18)*
EQ-5D pain/discomfort	-0.61	0.54 (0.07–4.47)	-0.34	0.71 (0.28–1.85)
EQ-5D anxiety/depression	1.31	3.72 (0.95–14.57)*	0.24	1.27 (0.55–2.95)
EQ VAS(health today) ⁷	0.01	1.01 (0.98–1.05)	0.01	1.01 (0.99–1.03)*
Baseline OKS	0.11	1.12 (0.99–1.26)*	0.14	1.15 (1.07–1.23)*
Operative side	0.58	1.79 (0.47–6.87)	0.23	1.26 (0.63–2.512)
Days of hospitalisation	-0.34	0.71 (0.25–2.04)	-0.02	0.98 (0.68–1.41)

Note. B = log odds ratio; OR = odds ratio; CI = confidence interval, * P value < 0.25.

Predictors of patients who are likely to have higher care needs

In total, 41 patients (20.4%) did not achieve an improvement in OKS \geq 9.6 points, indicating higher care needs. Eight variables were included in multiple regression analysis using forward selection based on findings from simple regression. The best variables for identifying patients with higher care needs were the presence of diabetes

⁶ Table 6 is an extract of Table 3 in Paper II.

⁷ The EQ-VAS asks patients about their overall health from ‘worst possible’ to ‘best possible’ on a VAS scale.

mellitus and baseline OKS (Table 7)⁸. The full model was statistically significant, $\chi^2 = 28.03$, $p < 0.01$.

Table 7. The best predictors of higher care needs.

Predictors	B	Adj. OR	P	95% CI
Preoperative OKS (per unit increase in score)	1.14	1.15	< 0.01	(1.08–1.24)
Diabetes mellitus	1.20	3.31	< 0.01	(1.55–7.08)

Note. B = log odds ratio; Adj. OR = adjusted odds ratio; CI = confidence interval.

Predictors of patients who are likely to have intensive care needs

In all, nine patients (4.5%) did not achieve an improvement in OKS ≥ 2.88 points, indicating higher care needs. Seven variables were included in multiple regression analysis using forward selection based on findings from simple regression. The best variables for identifying patients with higher care needs were number of comorbidities, anxiety/depression (EQ-5D), prior surgery in the operative knee, and baseline OKS (Table 8)⁹. The full model was statistically significant, $\chi^2 = 18.03$, $p = 0.01$.

Table 8. The best predictors of intensive care needs.

Predictors	B	Adj. OR	P	95% CI
Preoperative OKS (per unit increase in score)	0.15	1.16	0.02	(1.02–1.31)
Number of comorbidities	0.75	2.12	0.02	(1.13–3.97)
Anxiety/depression (EQ-5D)	2.33	10.27	0.01	(1.85–6.80)
Prior same knee surgery	1.95	7.00	0.02	(1.29–8.07)

Note. B = log odds ratio; Adj. OR = adjusted odds ratio; CI = confidence interval.

5.3. CONCLUSION

This study suggests that preoperative OKS and the presence of diabetes mellitus are associated with proxies of higher care needs (i.e., moderate and poor improvement), while number of comorbidities, presence of anxiety/depression, prior knee surgery and preoperative OKS seems to be associated with proxies of intensive care needs (i.e., poor improvement). Further research with a larger sample size is necessary to validate the results, especially with regard to the secondary analysis of patients with

⁸ Table 7 is an extract of Table 4 in Paper II.

⁹ Table 8 is an extract of Table 5 in Paper II.

intensive care needs, as the results may be over- or under-estimated due to the low number of patients in the group considered to have intensive care needs.

CHAPTER 6. STUDY III

This chapter summarises the work conducted in the paper entitled “*The potential of dividing the Oxford Knee Score into subscales for predicting clinically meaningful improvements in pain and function of patients undergoing total knee arthroplasty*” submitted for publication in the International Journal of Orthopaedic and Trauma Nursing (2021).

6.1. METHODS

Research design

This study was a retrospective observational cohort study with 201 consecutive patients undergoing total knee replacement surgery (the same study sample as in Study II). The study was reported in conformity with the STROBE guidelines (127).

Aims

The primary aim of the study was to assess the potential of dividing the OKS into subscales for predicting clinically meaningful changes in pre- and postoperative pain and function by comparing two different versions of extracting pain and function from the OKS.

Outcome measures

Outcome measures were changes, from baseline to one-year postoperative, in the ‘OKS pain component’ and the ‘OKS function component’ extracted from the summary OKS. Two versions of these components were analysed, as shown in Table 9¹⁰. The outcomes were dichotomized to determine whether the patients obtained a clinically meaningful change in the two versions of the pain and function component using an anchor-based approach (134). The scores in each subscale were converted to a standardised 0–100 scale (0 = best score; 100 = worse score) to allow for meaningful comparison between the two components.

Predictor variables

In all, 21 predictor variables were included: gender, age, body mass index, marital status (married/unmarried), VAS in activity and at rest, presence of diabetes mellitus, number of comorbidities, prior knee surgery, surgical side, length of hospital stay, OKS (total, pain and function), EQ-5D index score, EQ-VAS and each of the five

¹⁰ Table 9 is an extract of Table 1 in Paper III.

domains in the EQ-5D descriptive system: mobility, self-care, usual activities, pain/discomfort and anxiety/depression.

Table 9. Distribution of the pain and function questions in the two versions¹¹.

Questions	V ¹	V ²
How would you describe the pain you usually have from your knee?	P	P
Have you had any trouble with washing and drying yourself?	F	F
Have you had any trouble getting in and out of your car/public transport?	F	F
How long have you been able to walk before pain becomes severe?	P	P
After a meal (sat at a table), how painful has it been to stand up from a chair?	P	P
Have you been limping when walking?	P	F
Could you kneel down and get up again afterwards?	F	F
Have you been troubled by pain from your knee in bed at night?	P	P
How much has pain from your knee interfered with your normal work?	P	P
Have you felt your knee might suddenly 'give away' or let you down?	P	F
Could you do the household shopping on your own?	F	F
Could you walk down one flight of stairs?	F	F

Note. V¹: version 1, V²: version 2.

Statistical analysis

Multiple logistic regression analysis with forward selection was applied to investigate the association between the potential predictor variables and changes in the two versions, V¹ and V², of the pain and the function components. Metrics for comparison between V¹ and V² included the omnibus test of model coefficients, Nagelkerke's R² and the area under the curve (AUC) (135). An AUC of 1 indicates perfect discrimination, and an AUC of 0.5 indicates discrimination no better than change (136). The sample size calculation was performed as suggested by Peduzzi et al., including ≥ 10 events per variable (137).

IBM SPSS Statistics 27 was used for analysis.

Anchor-based method for calculating threshold levels

This study used an anchor-based approach, using the EQ-5D pain/discomfort and EQ-5D usual activities to define threshold values for clinically meaningful changes in pain and function scores extracted from the summary OKS (Table 10)¹². The difference in the average changes in the pre- and post-operative pain and function components in the group of patients who replied 'no problems' and 'moderate problems' were used to define the threshold for the outcomes, e.g., patients not obtaining a change in pain and/or function above the calculated threshold were assumed to have increased care needs. The appropriateness of using the anchors was initially assessed by investigating

¹¹Table 9 is modified from reference (128).

¹² Table 10 is an extract of Table 3 in Paper III.

the correlation between each of the anchors and changes in pre- and post-operative pain and function (138). The correlations between anchors and changes in each of the two versions of the pain and function components were all higher than 0.30 ($p < 0.001$).

Table 10. Threshold values.

Version	Thresholds
<i>Version 1</i>	
OKS pain	41.97
OKS function	22.54
<i>Version 2</i>	
OKS pain	42.39
OKS function	28.83

Note. The threshold values are presented on a 0–100 scale.

6.2. RESULTS

Comparison of version 1 and version 2

Version 1

For pain, 98 of the patients (48.8%) did not report a change above the calculated threshold of 41.97. The best predictors were diabetes mellitus, preoperative VAS pain at rest and preoperative pain extracted from OKS (V^1). For ‘goodness of fit’, the chi-square value of the omnibus test of model coefficients was 57.63 (p -value < 0.01). Nagelkerke’s R^2 value was 0.33, suggesting that 33% of the variability is explained by the included variables. This model yielded an AUC of 0.794 (Table 11)¹³.

For function, 94 (44.8%) did not report a change above the threshold of 22.54. Three predictors were included in the model: sex, diabetes mellitus, and preoperative function extracted from OKS (V^1). The chi-square value of the omnibus test of model coefficients was 49.573 (p -value < 0.05). Nagelkerke’s R^2 was 0.293. The AUC of this model was 0.776 (Table 11).

Version 2

For pain, 94 patients (46.8%) did not report a postoperative change in pain above the calculated threshold of 42.39. After forward selection of variables, five variables were included: age, diabetes mellitus, VAS pain at rest, preoperative EQ-5D (mobility), and preoperative pain extracted from OKS (V^2). Nagelkerke’s R^2 was 0.322. The chi-

¹³ Table 11 is an extract of Table 6 in Paper III.

square value of the omnibus test of model coefficients was 55.408 (p-value < 0.01). This model yielded an AUC of 0.790 (Table 11).

For function, 107 patients (53.2%) did not report a functional change above the threshold of 28.83. After forward selection, two predictors were included in the model: diabetes mellitus and preoperative function extracted from the OKS (V^2). The omnibus test of model coefficients using the chi-square value was 57.776 (p-value < 0.05). Nagelkerke's R^2 was 0.334, and the model yielded an AUC of 0.791 (Table 11).

Table 11. Comparison metrics.

	Chi-square	Nagelkerke's R^2	AUC
<i>Version 0</i>			
Summary OKS	49.524	0.291	0.776
<i>Version 1</i>			
OKS pain	57.625	0.332	0.794
OKS function	49.573	0.293	0.776
<i>Version 2</i>			
OKS pain	55.408	0.322	0.790
OKS function	57.776	0.334	0.791

6.3. CONCLUSION

In conclusion, it seems reasonable to separate the summary OKS into an OKS pain component and an OKS function component to predict clinically meaningful changes in pre- and post-operative levels of pain and function. Overall, the best performing version was V^2 consisting of questions 1, 4, 5, 8 and 9 for the OKS pain component and questions 2, 3, 6, 7, 10, 11 and 12 for the OKS function component. Although this study primarily focused on the potential of subdividing the OKS into separate subscales, the study also provided suggestions for threshold values for clinically meaningful changes in the pre- and post-operative pain and function components. The best predictors of patients not achieving clinically meaningful changes in pain and function were age, diabetes, pain at rest, EQ-5D mobility and the preoperative OKS pain and function components.

CHAPTER 7. STUDY IV

The description of study IV is based on the paper “*Predicting patient-reported outcomes indicating enhanced care needs for managing function and pain in patients undergoing total knee arthroplasty: a development study*” submitted to Nursing Research (2021).

7.1. METHODS

Research design

Study IV was a developmental study using various traditional statistical and machine learning approaches for building prediction models. The study used the same sample of 201 patients as in studies II and III. The guidelines of the Transparent Reporting of a multivariable prediction model for Individual Prognosis Or Diagnosis statement (TRIPOD) were followed (139,140).

Aim

The aim of this study was to use traditional statistics and machine learning to develop prediction models for identifying patients who are likely to have increased care needs related to managing pain and function as described by the OKS function and pain components.

Outcome measures

Outcome measures were pre- and post-operative changes in the OKS pain and function components extracted from the OKS. The OKS pain component included 5 questions ranging from 0 to 20, while the OKS function component included 7 questions ranging from 0 to 28. To standardise the two components on a 0–100 scale, the sum of the pain component score was multiplied by 5, and the sum of the function component score was multiplied by 3.57, meaning, for example, that a total score of 12 in the function component was congruous with a standardised score of 60.

For regression modelling (continuous outcome), outcomes were direct changes in the pre- and post-operative pain component and function component. For classification modelling (binary outcome), threshold values for clinically meaningful changes of 42.39 (pain component) and 28.83 (function component) were applied using an anchor-based approach in Study III.

Predictor variables

In all, 21 predictor variables were included (the same as in Study III).

Model building

Model selection

The following models were chosen for comparison of performance after spot checking: logistic regression, linear regression, linear discriminant analysis, CART, K-nearest neighbours, support vector machine, random forest, cubist and stochastic gradient boosting.

Model evaluation metrics

The performance of the models was investigated by different evaluation metrics:

In regression modelling, the root mean square error (RMSE) was used as an outcome metric in model generation (training set), while the mean absolute error (MAE) and R^2 were used as comparison metrics. In classification modelling, the AUC of the receiver operator characteristics curve (ROC) was used as an outcome metric for optimisation and comparison, and the sensitivity and specificity were applied. Confusion matrices were used to quantify accuracy.

Cross-validation

To prevent overfitting, ten-fold cross-validation was applied including 1) splitting data randomly into ten equal subsets, 2) dividing the ten subsets into two parts: one subset was kept aside for a later test and validation, while the other nine subsets were used for training the models 3) this process was repeated ten times and results were summarised in a table as minimum, first quartile, median, mean, third quartile, and maximum.

All calculations were carried out using the caret package in R-statistics software version 4.0.2.

7.2. RESULTS

The performance of the models predicting the difference in the pain and function component from baseline to follow-up.

Regression modelling:

For the pain component, the best mean RMSE (18.22), mean MAE (15.20) and mean R^2 (0.23) were obtained with the stochastic gradient boosting model. For the OKS

function component, the best mean RMSE (13.90), mean MAE (11.18) and mean R^2 (0.40) were obtained with the support vector machine model.

Classification modelling:

For the pain component, the gradient boosting model delivered the best AUC of 0.73, yielding a sensitivity and specificity of 0.55 and 0.73, respectively. It can be seen from the confusion matrix that 51 of 94 patients were correctly classified as having a change in the pain component score < 42.39 (true positives), whereas 78 of 107 were correctly classified as having a positive change in pain ≥ 42.39 (true negatives) (Table 12)¹⁴.

Table 12. Confusion matrix (pain).

Predicted	Actual		Total
	OKS pain < 42.39	OKS pain ≥ 42.39	
OKS pain < 42.39	51	29	80
OKS pain ≥ 42.39	43	78	121
Total	94	107	201

For the functional component, the random forest model delivered the best AUC of 0.77, giving a sensitivity and specificity of 0.69 and 0.67, respectively. In all, the confusion matrix shows that 74 of 107 patients were correctly classified as having a change in the function component < 42.39 (true positives), whereas 62 of 94 patients were correctly categorised as having a positive change in function ≥ 42.39 (true negatives) (Table 13)¹⁵.

Table 13. Confusion matrix (function).

Predicted	Actual		Total
	OKS function < 28.83	OKS function ≥ 28.83	
OKS function < 28.83	74	32	106
OKS function ≥ 28.83	33	62	95
Total	107	94	201

¹⁴ Table 12 is an extract of Table 6 in Paper III.

¹⁵ Table 13 is an extract of Table 6 in Paper III.

7.3. CONCLUSION

This study indicates that it is possible to use routinely collected data in our hospital to predict clinically meaningful changes in the pain components and functional components extracted from the OKS, implying enhanced care needs for managing function and pain. The predictive performance of the models for predicting function was higher than that of the models for predicting pain. The best models demonstrated acceptable performance with AUCs of 0.73 and 0.77 for pain and function, respectively. Further development and validation of the models are needed before implementation in clinical practice.

CHAPTER 8. DISCUSSION

In this chapter, the results derived from studies I-IV will be discussed in context with the existing literature and the overall aim of the thesis. This will be followed by methodological considerations in which the strengths and limitations will be discussed. Finally, implications for practice will be discussed, and prospects for future research will be outlined.

8.1. SUMMARY OF MAIN FINDINGS

This thesis aimed to investigate the potential of identifying patients who might have enhanced care needs in the accelerated care pathway. This included identification and synthesis of patients' pre- and post-operative experiences of information and prediction of changes in the pre- and post-operative OKS. The premise of the research was that information is a fundamental care need of patients and that self-reported changes in pre- and postoperative OKS can be used as a suitable proxy to identify patients who are likely to have enhanced care needs for managing their conditions.

Study I illustrated the complexity of information from health care professionals used to assist patients in the management of their conditions throughout the accelerated care pathway. The study revealed that some patients have positive experiences with receiving information, yet other patients experience severe challenges in managing continued pain and functional limitations during recovery and request enhanced information and guidance from health care professionals. The evidence presented in this study underpinned the need to identify patients experiencing challenging recoveries due to inadequate improvements in pain and function, as they seem to have enhanced care needs. *Study II* suggested the best preoperative predictors of patients with enhanced care needs were baseline OKS and diabetes mellitus (higher care needs) and baseline OKS, number of comorbidities, anxiety/depression, and prior same knee surgery (intensive care needs). *Study III* indicated that it is reasonable to divide the summary OKS into a pain component and a functional component for predicting clinically meaningful changes in pain and function. The models (V^2) including five questions in the pain component (questions 1, 4, 5, 8 and 9) and seven questions in the function component (questions 2, 3, 6, 7, 10–12) presented the best overall model performance. *Study IV* demonstrated acceptable performance for predicting patients without clinically meaningful changes in pain and function with AUCs of 0.73 and 0.77, implying that the models have the potential to identify patients who are likely to have enhanced care needs for managing pain and function postoperatively.

8.2. DISCUSSION OF MAIN FINDINGS

The discussion of the main findings includes the following areas: 1) predictive modelling for identifying patients with enhanced care needs, 2) patients who may require enhanced care, 3) moving beyond a ‘one-size-fits-all’ approach in clinical care, 4) improving patients’ ability to manage their postoperative conditions, and 5) prediction models to assist health care professionals in patient care decisions.

Predictive modelling for identifying patients with enhanced care needs

The findings of this thesis demonstrate the potential of applying prediction models to identify patients with inadequate improvement in pain and function who are likely to have enhanced care needs for managing their conditions after knee replacement surgery. While Study I demonstrated the necessity to identify patients struggling with managing continued pain and functional limitations, Studies II-IV showed the possibility of using routinely collected clinical data and PROMs to develop prediction models to identify patients with continued pain and functional limitations after surgery. The prediction models in Study IV showed acceptable performance for predicting clinically meaningful changes in pain and function using threshold values derived from Study III. The AUC values of the best prediction models were 0.73 for predicting the OKS pain component and 0.77 for predicting the OKS function component. Although the best model for predicting patients’ challenges with function showed better performance compared to the best model for predicting patients’ challenges with pain, both models showed acceptable model performance with AUC values between 0.7 and 0.8 (135). The measures of model discrimination in Study IV are in line with the results from previous models predicting the OKS, with AUC values ranging between 0.71 and 0.77 (90–93). The previous models predicting the OKS differ from Study IV by predicting the summary OKS instead of separating the 12 questions into pain and function components (90–93). Three of these models predicting the OKS treated the outcome as a classification problem using logistic regression (92,93), and one of them used machine learning approaches (91). Of these comparative studies, Shim et al. obtained the best AUC of 0.77, which may be because they both incorporated clinical and psychosocial predictor variables (e.g., patient expectations and coping skills) (92). As in Study IV, Huber et al. (91) predicted the OKS with machine learning approaches using predictor variables comparable to those in Study IV, and they obtained an AUC value of 0.71. As opposed to treating the outcome as a classification problem, Sanchez-Santos et al. (90) developed a prediction model using linear regression and obtained an R^2 value of 0.18 (development cohort). The best models in Study IV provided an R^2 value of 0.23 for the pain component and an R^2 value of 0.40 for the function component. The better results obtained in Study IV compared to previous studies developing prediction models may partly be explained by predicting the OKS outcomes for pain and function separately.

Patients who may require enhanced care

The synthesised findings of Study I indicated that patients with deprived physical and psychological health have decreased resources for managing their rehabilitation and care at home after surgery. This seems to be consistent with the findings from Study II and Study III, suggesting that patients with comorbidities have worse outcomes related to continued pain and functional limitations. The presence of comorbidities has also been identified in previous studies as an important predictor of worse outcome in patients undergoing knee replacement surgery (90,118,141). Study II also suggested that there may be an association between the presence of depression/anxiety in patients and poor outcomes as measured by the self-reported OKS. This is also consistent with previous studies finding associations with preoperative anxiety/depression and worse postoperative outcomes (26,90,142). Although the reasons behind this association between anxiety/depression and outcomes may be multifactorial, patients in Study I reported that feeling anxious exacerbated their ability to take in and comprehend information from health care professionals, which affected their ability to manage their condition after the surgery. Both Study II and Study III found that baseline pain and function are strong predictors of the outcome, which is also in line with previous research (90,91). Study I suggested that patients who have not undergone knee replacement surgery previously experience more insecurity and lack an understanding of what to expect during rehabilitation at home. Information on whether patients had undergone a previous knee replacement surgery in the other knee was not available in Studies II-IV. However, Study II suggested that patients who have had a prior surgery on the same knee (e.g., arthroscopy) may have an increased risk of poor outcomes. Prior surgeries on the same knee were another kind of surgery; thus, it may not have been possible for patients to draw on these experiences to manage their current surgery and condition. In Study III, it appeared that age and gender may have influenced outcomes. However, the literature has shown more inconsistent associations with demographic characteristics (age, sex and body mass index) and outcomes after knee replacement surgery (141). Although Study II and Study III did not provide strong evidence of factors and characteristics of patients who are likely to have enhanced care needs, the findings provide a sense of which variables may drive predictions.

Moving beyond a ‘one-size-fits-all’ approach in clinical care

The prediction models in this thesis offer the potential to help health care professionals focus future interventions on the patients who are most in need and where the impact of providing enhanced care resources might be the greatest. Previous research investigating the effect of nurse-led care interventions with postoperative telephone consultations has been conducted to accommodate patients’ postoperative care needs after knee replacement surgery; however, these studies have not shown any effects with regard to optimised pain management and regained function as well as other outcomes following TKA (143–145). These interventions were provided to all

patients undergoing knee replacement surgery; however, patients seem to differ in the amount of information and guidance they needed from health care professionals to manage their condition, as also suggested in Study I (143–145). Therefore, it remains unknown whether inclusion of all patients in trials evaluating the effect of nurse-led telephone consultations obscured a possible effect in the subgroup of patients with enhanced care needs who may have been more likely to benefit from the intervention. This raises an interesting question of whether future interventions will become more sustainable if the interventions are concentrated on patients at risk of developing postoperative problems (80). Tailoring interventions to patients' individual clinical conditions and care needs has previously been thought to show considerable promise in improving health behaviour and outcomes across patient populations (2,146–148).

Improving patients' ability to manage their postoperative conditions

The separation of the OKS into pain and function components for predicting clinically meaningful changes in pain and function offers the possibility of broadening the application of OKS from use as a tool to determine the overall success of surgery to be used as a tool to identify the need for increased information and support to manage pain and/or functional limitations. Study I showed that patients with a difficult recovery encounter numerous challenges that they had not considered before discharge and that continuing information and guidance from health care professionals are essential to increase their confidence and ability to manage continued pain and functional limitations. It also appeared from Study I that patients do not necessarily disclose their problems and contact health care professionals for information and guidance for coping with their conditions postoperatively. The identification of patients who are likely to have enhanced care needs is crucial to improve the care of patients undergoing knee replacement surgery, as unidentified care needs may negatively affect health behaviour and surgical outcomes (2,4). The importance of identifying patients with challenging recoveries is also complemented by studies showing that health care professionals tend to overestimate patients' abilities to manage their rehabilitation at home, resulting in unidentified and unmet patients care needs (8,69). Patients having unidentified needs in clinical care may possibly be a contributory cause of higher pain levels than recommended (45.6%), and many patients do not exercise as recommended after knee replacement surgery (69.8%) (7). The findings of Study I also revealed that patients with suboptimal coping of challenges with pain and functional limitations often have clinical problems such as feelings of hopelessness, discouragement, and depression long after surgery.

The information gained from the prediction models may also serve as a basis for improving the dialogue between the patients and health care professionals based on specific information about patients' predicted challenges with pain and/or functional limitations. Findings from Study I pointed to the importance of health care professionals encouraging more dialogue with patients to tailor interventions to their individual care needs. Study I also revealed that some patients had unclear

expectations before surgery, and they described how they struggled with unfulfilled expectations because of continued pain and functional limitations postoperatively. Field et al. (149) proposed that information gained from PROMs offers an opportunity for health care professionals to identify and discuss patients' expectations of the surgery at an early stage. Thus, information gained from the prediction models may also be used to initiate discussions with patients about their expectations, help them set realistic expectations and determine how they best can be supported during and after discharge.

Prediction models to assist health care professionals in patient care decisions

Although the developed prediction models show promise in identifying patients who are likely to have enhanced care needs, assessing patients' care needs solely on prediction models is not possible. Liu et al. (150) noted that prediction models in clinical care should be seen as a useful tool for assisting health care professionals in decision-making rather than replacing decision-making. There are two main reasons for this. First, there is a risk of incongruence between the outcomes predicted by the models and the true outcomes (151). On the one hand, the patient may risk being identified as not having enhanced care needs when they actually have enhanced care needs (false negative), and thus interventions may not be offered leading to unmet care needs. On the other hand, patients may be identified as having enhanced care needs when they do not (false-positive), and there is a risk of spending limited resources on patients without a need for enhanced care (151). Second, the prediction models offer actionable information to identify patients who are likely to have enhanced care needs, yet the prediction models will not provide complete answers to health care professionals about how to accommodate patients' needs. Further, the developed prediction models will not capture other possible problems and care needs a patient may have, e.g., possible problems with wound infections or urinary infections. Health care professionals should therefore always base their decisions about clinical care on their own clinical judgement in a collaborative relationship with the individual patient (66,150). The importance of health care professionals building a collaborative relationship with patients to meet their needs throughout the care pathway also agrees with findings from Study I. This corresponds well with the purpose and process of evidence-based practice, which is an approach to the delivery of care that advocates for combining knowledge from research and patient care data with the clinical expertise of health care professionals and patients' own preferences (152). In this way, the prediction models in this thesis may be a way to facilitate and promote a patient-centred and evidence-based practice in clinical care.

8.3 METHODOLOGICAL CONSIDERATIONS

The strengths and limitations of each of the four thesis studies will be elaborated on in this section. Some of the methodological issues discussed apply in Studies II, III and IV and will therefore only be described once.

8.3.1. STUDY I

There was a clear reasoning for undertaking the systematic review and narrative synthesis, as no previous reviews have sought to identify and synthesise knowledge of how patients undergoing knee replacement surgery experience pre- and post-operative information provided by health care professionals. Patients' experiences with information have primarily been studied in separate phases along the care pathway, e.g., during preoperative education.

The main strength of Study I was the systematic approach that was obtained by adhering to the guidance on the conduct of narrative synthesis in systematic reviews (124). This required following specific steps to minimise the risk of bias and drawing misleading conclusions (124). Therefore, the narrative synthesis in this study differs from the traditional narrative review with a lower evidence level, as the former refers to a specific approach applied in a systematic review process (124). In addition, the PRISMA guidelines were applied to provide transparency in the reporting of the review. To eliminate potential flaws, two reviewers independently assessed the review-specific relevance and quality of the included peer-reviewed studies using critical appraisal instruments. This approach allowed for discussions between reviewers, which is important, as some studies may be borderline for inclusion, and the decision to include the study may possibly sway the results. The reviewers assessed the included studies to be of moderate to high quality, which supports the trustworthiness of the findings. A broad search strategy in four databases was undertaken with assistance from a research librarian, resulting in a large number of studies to assess. Although efforts were made to ensure an exhaustive survey of the studies, there is always a risk that studies have been missed or overlooked (126). Additionally, the restriction of studies published in Scandinavian and English languages may have caused selection biases.

The studies included in the synthesis had diverse methodological approaches and originated from various countries and hospitals with diverse cultures. Therefore, the systematic approach applied in the synthesis process was a prerequisite for the analysis of findings across studies. There were convincing similarities in patients' experiences of information from health care professionals throughout the care pathway, enabling inferences and conclusions to be drawn across settings. This may conceivably be explained by the standardisation of the organisation of treatment and care provided to patients undergoing knee replacement surgery.

8.3.2. STUDIES II-IV

Using the OKS as a proxy of patient care needs for managing pain and function

The use of the OKS as a proxy measure indicating patient care needs for managing pain and function might have both advantages and disadvantages. A strength of the

OKS is that it is a validated patient-reported and condition-specific measure resembling an overall aggregate of patient challenges with pain and function in daily activities. In addition, the use of the OKS does not provide an extra burden for health care professionals, as the data are already routinely collected in many hospitals. However, although the OKS is a validated patient-reported measure of patients' potential challenges with pain and function, it is limited because it has not been validated as a method for identifying patients who are likely to have enhanced care needs for managing pain and function. The OKS does not consider whether the patients (or health care professionals) perceive that they have enhanced care needs. It is therefore unknown whether the OKS, as a tool for identifying patients with enhanced care needs, tends to over- or under-estimate patient care needs. Another instrument, the patient classification instrument (PCI), has previously been used for measuring patients' care needs, yet this instrument was not considered appropriate in the context of this research, as it intends to measure the care needs of patients across populations to assess nursing workload (153). In addition, the PCI has been criticised for underestimating patients' actual care needs and for being tedious and cumbersome to use (153,154). In contrast, the OKS is tailored to the challenges to daily activities of patients who have undergone knee replacement, and the OKS is quickly completed by patients (it will typically only a few minutes to fill out) (155).

Study II

Study II was a descriptive correlational study using a wide range of parameters to identify the best predictors of patients with moderate or poor improvement in the OKS who are likely to have enhanced care needs. The study used routinely prospectively collected data from the DKR (patient characteristics and surgical information) and from Jointbase (PROM) with high completion rates (156). The prospective collection of data in the databases increased reliability and reduced risk of bias in the process of collecting data (157).

Study II was subject to a number of methodological weaknesses to consider. First, a major concern is that the study was constrained by the sample size. In particular, the small number of patients in the group assumed to have more intensive care needs (secondary outcome) made it difficult to achieve conclusive results. The more predictor variables included to influence the outcomes of interest, the more data needs to be sampled to predict these multifaceted interactions (131). Although other studies have confirmed the importance of the identified predictor variables, further studies are needed to confirm the findings of the present study. Second, although benefits from using routinely and readily available data exist, the research may have been limited because other possible predictor variables were not measured and included. Third, the study is also limited by the lack of information on patients not agreeing to provide informed content. This might pose a potential selection bias, as the participating patients might be different from those patients who did not agree to participate. However, preoperative patient characteristics in our group of patients

generally appear to be consistent with data reported in other studies. Finally, another point of discussion is that the applied threshold values in Study II were based on the opinions of a group of experts, which has some inherent weaknesses compared to methods using objective measures (158,159).

Although the findings of Study II should be interpreted with caution, the results indicate that there is information in the data for developing models that predict changes in pre- and post-operative OKS in patients undergoing knee replacement surgery.

Study III

Study III was a retrospective observational cohort study using the same sample of patients as in Study II. The sample size in Study III is comparable to the number of patients included in similar studies focusing on dividing the OKS questions into pain and function components (108,115). The study also suggested variables that may be predictors of patients not reaching a clinically meaningful improvement in pain and/or function components. Although this study complied with suggestions of the number of patients to include in logistic regression, some previous studies that focused on identifying predictors of the OKS have included more patients than this study did, resulting in higher validity (116,160). However, this study found many of the same predictors as those found in larger studies.

As part of the analysis, Study III also provided suggestions for threshold values for clinically meaningful changes in the pre- and post-operative pain and function components. An asset of this study is that an anchoring method was applied for calculating clinically meaningful changes based on the personal experience of the patients using the EQ-5D components (pain/discomfort and usual activities) as external anchors. Previous studies have used opinion-based and distribution-based approaches, which have some limitations. As discussed earlier, the opinion-based method has some inherent weaknesses (158,159). The distribution-based method relies on statistical characteristics of the patient sample; however, this method is considered to be weakened by a failure to incorporate the perspective of the patient (159). Therefore, calculation of threshold values using an anchor-based approach and components from the EQ-5D to define clinically meaningful changes in the OKS seems to be the most appropriate method to classify patients according to whether they are likely to have enhanced care needs. Another point of discussion is whether the threshold values of clinically meaningful changes should be based on patients' preoperative OKS, as patients with high preoperative pain levels might require a higher reduction in pain to reach an appropriate improvement compared to patients with less pain before the surgery (159,161).

Study IV

The main strength of Study IV was that a broad variety of machine learning and statistical models were applied to identify the best performing models. Machine learning and traditional statistical methods are converging by drawing knowledge from data, yet there are some distinctions (162). A strength of machine learning has been described as the ability to select and weigh predictor variables among a large amount of available data to model nonlinear interactions and to find new patterns in data (162). Although this represents a strength of machine learning models, it might also be considered a limitation in clinical care, as the models are typically less interpretable than traditional statistical models (120). Another angle to consider is that when the complexity of the models increases, there is also a higher risk of overfitting. Ten-fold cross-validation was applied to prevent the models from overfitting the training dataset. Overall, there was consistency in the results across the various prediction models in this study, suggesting a robustness of using the data in the models for predicting clinically meaningful changes in pain and function.

Because the prediction models were developed based on routinely collected data, the application in clinical care will not pose an extra burden on health care professionals to collect information, which may increase the acceptance of using the model. However, although the models, including easily available variables, generally demonstrated acceptable performances, the incorporation of psychosocial variables (e.g., coping skills, education and social deprivation) may have improved their performance.

Last, prediction models are likely to perform better in development samples than in new patients (163). Therefore, to improve the external validation of the models and thereby generalise the predictions to the general population of patients undergoing knee replacement surgery, the models should be further tested and validated in a larger and new sample of patients.

8.4. IMPLICATIONS FOR CLINICAL PRACTICE

The prediction models may be used as a tool to help health care professionals identify patients who are likely to have enhanced care needs for managing pain and functional limitations after knee replacement surgery. The accelerated care pathway is based on a multidisciplinary collaboration of health care professionals for providing the best treatment and care of patients undergoing knee replacement surgery (28). As the core concept of the accelerated care pathway is multiprofessionalism and includes a shared treatment method, the prediction models, as a tool to identify patients with enhanced care needs, may be of interest to all members of the health care team. Although the findings may be relevant for all health care professionals involved in the care of patients undergoing knee replacement surgery, orthopaedic nurses are often the most consistent caregiver for the patient and are responsible for coordinating care

throughout the accelerated care pathway (43). In addition, orthopaedic nurses at hospitals have in recent years been taking over some tasks from physiotherapists and surgeons, e.g., tasks for mobilisation and pain management (13,43). Hence, orthopaedic nurses may therefore possibly act as a bridge between the hospital and home for patients with enhanced care needs.

Clinical decision support tools with integrated prediction models have previously been developed in clinical care, yet many of them have not been accepted for use (150). The question of how to use and implement prediction models in clinical care remains unknown, yet digital and online interventions have been promoted as a valuable means of delivering care to patients undergoing knee replacement (13). In addition, previous prediction models that have gained acceptance in clinical care have been integrated into online tools (164). However, it is important to consider potential barriers for usage, such as the risk of impractical processes and time constraints in clinical care (164). For example, if the tool is not integrated into the existing electronic health record, health care professionals may need to log into various electronic sources, which might be a barrier for acceptance in clinical care. Another factor to consider is the usability of such a tool, as user experiences play a significant role in achieving the value of such solutions in clinical care (164). Therefore, questions of how to implement the prediction models in clinical care are important to consider and warrant future investigation.

8.4. IMPLICATIONS FOR FUTURE RESEARCH

This thesis research has raised many questions in need of further investigation. First, it is recommended that further research be undertaken to test and validate the prediction models on a new and larger patient sample that has not been used for training the models. This is crucial to externally validate the models to ensure that the results can be generalised. Further research could also be conducted to explore the effect of incorporating psychosocial predictor variables into the models, which seems to have the potential to improve the performance of the models. Another important issue to consider is that the clinical usefulness of the prediction models is sensitive to the proxies being used for identifying patients with enhanced care needs. Future research could therefore be carried out to explore the self-reported OKS (the pain and function components) as an instrument for identifying patients with enhanced care needs related to managing challenges with pain and functional disabilities. Further research may therefore investigate the agreement between patients identified as having enhanced care needs by the prediction models and their own perceptions of having enhanced care needs after knee replacement surgery.

The research in this thesis may serve as a basis for the development of future care interventions targeted to patients with enhanced care needs. Involvement of health care professionals in the earliest possible stage has been described as crucial when developing new interventions in clinical care to ensure that interventions will be

clinically effective and adapted to organisational and cultural contexts (165). Future research could apply participatory design approaches with multiprofessional health care professionals to develop interventions for patients struggling with continued pain and functional limitations (166). New care interventions should be tailored to the needs of the patients, and qualitative interview studies may provide a deeper understanding of the patients' preferences and needs for care initiatives to help them manage their conditions. Once a new intervention has been developed, studies will also be needed to test its efficacy in clinical practise, as the ultimate goal of developing prediction models is to improve patient care and outcomes (e.g., satisfaction, pain, function and quality of life).

CHAPTER 9. CONCLUSION

This last chapter concludes the thesis.

This thesis presents novel ideas and perspectives that have the potential to improve the care of patients undergoing knee replacement. Some patients experience inadequate postoperative improvements in pain and function after surgery and lack the information and support they need to manage their own care and rehabilitation. Many patients are reluctant to contact health care professionals for advice and guidance, and the information given is not always tailored to their specific care needs. The prediction models are considered promising for identifying patients without clinically meaningful improvement who are likely to have enhanced care needs for managing pain and functional limitations. The information gained from the prediction models may also serve as a base for improving the dialogue between patients and health care professionals. Although further research should be undertaken to refine and validate the models, this research is considered a first step towards moving beyond a ‘one size fits all’ approach to developing interventions that target the subset of patients at risk of not achieving clinically meaningful improvement and who are likely to have enhanced care needs. This is important, as patients with suboptimal coping of pain and functional limitations may experience innumerable clinical problems such as stress, hopelessness, and depression in addition to worse postoperative outcomes.

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APPENDICES

Appendix A Approval by the Danish Data Protection Agency

Appendix B Literature search

Appendix C The Oxford Knee Score (Questionnaire)

Appendix A. Approval by the Danish Data Protection Agency

Amanda Buus
Ortopædkirurgisk Afdeling
Hobrovej 18-22
9000 Aalborg

Godkendelse af forskningsprojekt under Region Nordjyllands paraplyanmeldelse

Det projekt, du har anmeldt: "Identifikation og modellering af helbredsrelateret outcomes hos knæalloplastik patienter", er omfattet af Region Nordjyllands paraplyanmeldelse ved Datatilsynet – Sundhedsvidenskabelig forskning i Region Nordjylland (2008-58-0028).

Projektet har id-nummer 2018-42, som du bedes oplyse ved eventuelle fremtidige henvendelser vedrørende projektet.

Projektet starter 2018-01-08 og slutter 2019-11-01.

Ved projektets afslutning opbevares data 2023-08-01 af hensyn til GCP-krav. (Det er et krav fra GCP-enhederne at forsøgsdokumenterne arkiveres i mindst fem år efter forsøgets afslutning).

Datagrundlaget for projektet er Procordodatabasen. Populationens størrelse er 220 bestående af knæalloplastik patienter tilhørende Aalborg kommune.

Dataansvarlig er Region Nordjylland med Amanda Buus som projektansvarlig.

Data opbevares i en RN-godkendt løsning og bearbejdes ved hjælp af IT løsninger stillet til rådighed og godkendt af Region Nordjylland.

Husk at være opmærksom på at gemme eventuel identifikationsnøgle med cpr-nr. forsvarligt adskilt fra forskningsdata på id-nummerniveau.

Bemærk at hvis der skal laves opslag i elektroniske patientjournaler uden en aktuel patient-behandler-relation eller et informeret patientsamtykke, gælder retningslinjen

Adgang til helbredsoplysninger i elektroniske systemer for særlige personalegrupper.
(Også vedhæftet).

Hvis du har spørgsmål eller andet, er du meget velkommen til at ringe eller maile til mig.

Med venlig hilsen

Christina Øllegaard Elmer

Sagsbehandler, forskningsanmeldelser

Appendix B. Literature search

Medline.

1. Arthroplasty, Replacement, Knee/
2. (knee adj2 (replacement or arthroplasty)).tw,kw.
3. Knee Prosthesis/
4. (joint adj2 (replacement or arthroplasty)).tw,kw.
5. knee.mp.
6. 4 and 5
7. Arthroplasty patient*.tw,kw.
8. 5 and 7
9. 1 or 2 or 3 or 6 or 8
10. patient* experience*.tw,kw.
11. exp Patient Satisfaction/
12. patient* concern*.tw,kw.
13. (wellbeing or well being).tw,kw.
14. (challenge* or attitude* or psychosocial* or emotion*).mp.
15. Adaptation, Psychological/
16. Stress, Psychological/
17. "health services needs and demand"/ or needs assessment/ or need.mp.
18. Fear/ or Frustration/
19. (fear or frustration*).tw,kw.
20. Patient Participation/
21. patient participat*.tw,kw.
22. patient involvement*.tw,kw.
23. (preference* or perspective* or perception* or expectation* or view*).tw,kw.
24. exp Self Care/ or (self adj (care or management*)).tw,kw.
25. or/10-24
26. "Length of Stay"/
27. (accelerated adj2 (care or discharge*)).tw,kw.
28. fast track*.tw,kw.
29. enhanced recovery.tw,kw.
30. perioperative period/ or postoperative period/ or preoperative period/
31. Intraoperative Period/
32. (postoperative or perioperative or preoperative or intraoperative).tw,kw.
33. eras.tw,kw.
34. rapid recovery.tw,kw.
35. hospitalization/ or patient admission/ or patient discharge/
36. (hospitaliz* or admission or discharge*).tw,kw.
37. Outpatient Clinics, Hospital/ or Ambulatory Care/

38. ((outpatient or out patient) adj3 (clinic* or setting*)).tw,kw.
39. Patient Education as Topic/
40. (information or education*).tw,kw.
41. exp Rehabilitation/ or rehabilitation.fs. or rehabilitat*.tw,kw.
42. or/26-41
43. 9 and 25 and 42
44. limit 43 to (yr="2005 -Current" and (danish or english or norwegian or swedish))
45. remove duplicates from 44

Appendix C. The Oxford Knee Score

The 12 questions in the OKS and the related response categories (128).

Questions	Response categories
1 How would you describe the pain you usually have from your knee?	(0) None (1) Very mild (2) Mild (3) Moderate (4) Severe
2 Have you had any trouble with washing and drying yourself?	(0) No trouble at all (1) Very little trouble (2) Moderate trouble (3) Extreme difficulty (4) Impossible to do
3 Have you had any trouble getting in and out of your car or using public transport?	(0) No trouble at all (1) Very little trouble (2) Moderate trouble (3) Extreme difficulty (4) Impossible to do
4 For how long have you been able to walk before pain becomes severe?	(0) No pain/> 30 min. (1) 16 to 30 min. (2) 5 to 15 min. (3) Around the house only (4) Not at all/severe on walking
5 After a meal (sat at a table), how painful has it been to stand up from a chair?	(0) Not at all painful (1) Slightly painful (2) Moderately painful (3) Very painful (4) Unbearable
6 Have you been limping when walking?	(0) Rarely/never (1) Sometimes or just at first (2) Often, not just at first (3) Most of the time (4) All of the time
7 Could you kneel down and get up again afterwards?	(0) Yes, easily (1) With little difficulty

- | | | |
|----|---|--|
| | | (2) With moderate difficulty
(3) With extreme difficulty
(4) No, impossible |
| 8 | Have you been troubled by pain from your knee in bed at night? | (0) No nights
(1) Only 1 or 2 nights
(2) Some nights
(3) Most nights
(4) Every night |
| 9 | How much has pain from your knee interfered with your normal work? | (0) Not at all
(1) A little bit
(2) Moderately
(3) Greatly
(4) Totally |
| 10 | Have you felt your knee might suddenly 'give away' or let you down? | (0) Rarely/never
(1) Sometimes or just at first
(2) Often, not just at first
(3) Most of the time
(4) All of the time |
| 11 | Could you do the household shopping on your own? | (0) Yes, easily
(1) With little difficulty
(2) With moderate difficulty
(3) With extreme difficulty
(4) No, impossible |
| 12 | Could you walk down one flight of stairs? | (0) Yes, easily
(1) With little difficulty
(2) With moderate difficulty
(3) With extreme difficulty
(4) No, impossible |
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ISSN (online): 2246-1302
ISBN (online): 978-87-7573-980-6

AALBORG UNIVERSITY PRESS